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ISBN: 1 920966 27 7

Please cite this article as:

McMahon J and Lawn S (2011) *Foundations for change: Part 2 - CARERS: Experiences of CARERS supporting someone with the diagnosis of Borderline Personality Disorder (BPD)*. Private Mental Health Consumer Carer Network (Australia): Marden, South Australia, Australia.

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# Foundations for Change

## **PART 2      Experiences of CARERS Supporting CARERS      Someone with the Diagnosis of                  Borderline Personality Disorder (BPD)**



Private Mental Health  
Consumer Carer Network (Australia)  
*engage, empower, enable choice in private mental health*

**Janne McMahon OAM  
Associate Professor Sharon Lawn  
December, 2011**

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ISBN: 1 920966 27 7

## **This is an Independent Report of the Data from a National Survey Undertaken by the Private Mental Health Consumer Carer Network (Australia)**

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### **The suggested citation for this document is:**

McMahon, J., Lawn, S. (2011). *FOUNDATIONS FOR CHANGE: PART 2- CARERS: Experiences of CARERS supporting someone with the Diagnosis of Borderline Personality Disorder (BPD)*. Private Mental Health Consumer Carer Network (Australia): Marden, South Australia, Australia.

## Acknowledgements

The Private Mental Health Consumer Carer Network (Australia) [Network] wishes to thank all carers who are affected by someone close to them with the diagnosis of Borderline Personality Disorder for speaking the truth of their experiences.

In having the courage to do so, we acknowledge their struggle and their strength. We acknowledge their courage to persist in the face of barriers.

We acknowledge every clinician who accepts and respects people affected by Borderline Personality Disorder, who provides a good level of care and who is a partner in that care.

And to all who work for better recognition for those affected as carer by Borderline Personality Disorder, who actively seek to reduce the prejudices and discrimination associated with this serious condition, and who strive to provide access to appropriate supports, we acknowledge your efforts.

The Network also wishes to thank Associate Professor Sharon Lawn, who has carefully translated the data into this report- *FOUNDATIONS FOR CHANGE: PART 2 CARERS: Experiences of carers supporting someone with the diagnosis of Borderline Personality Disorder*. We wish to acknowledge Mr. David Smith, Flinders University who assisted with further statistical analysis of some aspects of the data for this report. Lastly, we wish to thank the Australian Government, Department of Health and Ageing for providing funds to engage Associate Professor Richard Woodman, Flinders University who undertook a robust check of statistical analyses.

And finally, we wish to thank Janne McMahon OAM, a leading advocate for people affected by BPD and Network Independent Chair, who constructed the survey in consultation with expert consumers, carers and academics in the field of Borderline Personality Disorder and the Network's National Committee who have provided critical input and so positively supported this work.

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# Experiences of Carers Supporting Someone with the Diagnosis of Borderline Personal Disorder

## Executive Summary

128 carers supporting someone with BPD entered the survey site. Of these, 121 (95.0%) proceeded to answer survey questions, with 61 (50.4%) completed all questions, and 60 (49.6%) being selective in which questions they responded to.

Participation in the BPD carer survey was open to any carer who identified themselves as being a person whose family member had a diagnosis of BPD and were those that responded to an invitation to participate distributed in the first instance to 20 mental health service organisations and 29 consumer and carer networks across Australia, including clinical mental health service systems and community and non-government organisations with a request for on-forwarding to consumers and carers. The surveys were widely publicised and delivered online via 'SurveyMonkey' across Australia. The surveys were conducted between 27<sup>th</sup> May and 30<sup>th</sup> June 2011. It should be noted therefore that since the survey respondents were not a random sample from a population based sampling frame of BPD consumers, and were instead self-selected by virtue of choosing to participate in the survey, the extent to which the conclusions drawn from the survey are representative of the wider BPD population depends on the extent to which response bias may have existed. Similarly, many consumers that did participate were also selective of which questions they would answer, particularly later in the survey.

Carers from all States and Territories took part in the survey. Most of the 128 carers lived in metropolitan areas (62% - n=75) with 33.9% (n=31) living in regional towns and 4.1% (n=5) in remote areas. A disproportionate number of respondents lived in regional or rural areas compared to the Australian population. Similar to the patterns of consumer responses, this could be due to either a non-representative sample of BPD carers choosing to take part in the survey, or it could be due to differences in levels of perceived support amongst urban and regional carers, with isolation and other factors amongst regional carers, and these carers then expressing their voice in greater numbers.

Of the 19 carers that completed questions about their perceptions of early signs of BPD in the person they cared for, 57.9% (n=11) identified sensitivity as the main sign during infancy or toddlerhood, along with moodiness (42.1% (n=8), excessive separation anxiety (42.1% (n=8) and social delay (36.8% (n=7). During childhood, sensitivity rated highly (63.2% - n=12 of 19), along with difficulty making friends (63.2% - n=12), school refusal/truancy (52.6% - n=10) and being a victim of bullying (47.4% - n=9). These findings may have implications for how parents and schools respond to their child's diagnosis. During adolescence, anger was the most prominent issue that carers reported noticing (68.4% (n=13 of 19), followed by moodiness (63.2% - n=12), impulsivity (57.9% - n=11), body image issues (52.6% - n=10), and sensitivity (52.6% - n=10). Further issues - difficulty making friends was noted by 62.5% of carers (n=10), followed by promiscuity (56.3% (n=9) and verbally abusive outbursts (50% - n=8).

Seventeen carers sought an evaluation of their child's problems mainly as a result of concern about behaviour problems (70.6% - n=12) and mood disturbances (58.8% - n=10). Of note, a doctor or teacher recommendation to seek an evaluation scored low (17.6% - n=3 of 17). This paints a picture of not only a

young person rapidly losing control, but also of their parents increasingly impacted by multiple issues beyond that expected of childhood and adolescence, with little outside recognition or support.

The presence or not of existing comorbid mental illnesses amongst persons with BPD showed a different set of carer and consumer responses. This may have been a reflection of the different views of the carers and consumers on the way in which they understood theirs, or their supported person's illnesses, but may simply have been due to non-paired set of carer-consumer dyads responding to the surveys. Of particular note however, 41.0% of consumers (n=48 of 117) vs 20.0% of carers (n=16 of 80) ( $p=0.002$  for difference) reported post-traumatic stress disorder as a co-morbid condition.

Carers reported similar rates of consumers taking no medications (22.3%, n=21 of 94) to that reported by consumers (17.2%, n=21 of 122) ( $p=0.35$ ) and also reported similar rates of not knowing what medication they were taking (5.3% versus 1.6% respectively,  $p=0.13$ ).

Of 82 respondents, there were no support types that were universally rated as 'very helpful' by the carers. In addition, the helpfulness of support groups was quite mixed. These results suggest that carers of people with BPD may need more individualised support than that offered to carers of people with other mental health diagnoses. More than half of the 82 carers (56.1% - n=46) who responded to further questions about support stated that they had wanted to access support but had not been able to. Similar to consumers with BPD, being unable to access supports when needed (62.3%, n=48 of 77) and not being taken seriously (60.5%, n=46 of 76) were rated highly on the list of barriers experienced by carers.

Similarly to consumers with BPD, carers (n=70) rated as challenging, the full range of listed issues that may cause anxiety for the person they care for. This suggests that they have a very good understanding of the struggles the person with BPD faces when attempting to get support.

Psychiatrists were overwhelming the health professionals who made the first diagnosis according to carers' perceptions (87.0%, n=70 of 87). However, only one third (32.3% - n=30) of carers had the diagnoses explained to them and understood the explanation given.

Of 72 respondents, 51.4% (n=37) of carers said that their GP had not supported them as a carer and the report also suggests that GPs are even less likely to provide them with counselling to support their carer role with 76.1% of carers reporting that this support is not provided by their GP. Almost half of carers reported that the GP had not referred them to other supports. Later questions revealed that no professional group was prominent in carers' ratings of support for their role as carers, except GPs. GPs therefore still appear to be an important source of support for some carers. This varied little between metropolitan (50.0%) and rural locations (46.7%) ( $p=0.78$ ). It did however vary according to whether consumers had undergone private hospital admissions (68.7%, n=11 of 16), with carers of these consumers perceiving more GP support than those not admitted privately (n=8 of 23) ( $p=0.04$ ).

None of the professional groups were rated as 'very responsive' by 63 carers in the context of the person cared for when in crisis. GPs (63.8%) were more commonly rated as 'very responsive' or 'responsive' by carers (n=37 of 58) compared to other professionals, and psychiatrists were further noted as 'not responsive' (30.2%) (n=16 of 53) by a greater number of carers than any other profession.

Almost three quarters (72.5%, - n=29 of 40) of carers reported that the person they cared for had been admitted to hospital involuntarily, a similar figure to that reported by consumers (66% - n=35 of 53, p=0.50). Also, carers reported a substantial subset of consumers with BPD (22.5%) who were detained under the Mental Health Act for three days then discharged.

Almost half of carers (48.6%, n=18 of 37) reported that they had never been involved in the admission process for the person they cared for.

57.5% (n=23 of 40) of carers reported that they had experienced times when they had asked for the person they cared for to be admitted to hospital but had been refused.

55.4% (n=36 of 65 respondents) reported that mental health professionals had not helped them to understand early warning signs or when the person might be more at risk of suicide or self-harm. In addition, 73.4% (n=47 of 64 respondents) had not received a crisis plan from mental health service providers for the person they care for.

During a crisis, 33.3% (n=21 of 63) of carers reported a response from mental health professionals within two days and 66.7% (n=42 of 63) reporting a response of longer than this, which becomes concerning when we also acknowledge that the crisis points which carers and the BPD person often report as part of living with BPD as being common events. A substantial proportion of carers responding to a second version of the question within the self-harm/suicidal behaviours section of the survey which asked what was the longest time it took to get support for the person cared for after requesting it (23.4% - n=11 of 47) reported that they didn't get a response from services.

Seventy-five percent of carers reported that the person they care for had attempted to end their life in the past (n=45 of 60). This result is in contrast to the 100% of consumers who reported this. This result suggests that some carers may not be fully aware of suicide attempts by the consumers they care for and this is supported by consumers' self-report of non-disclosure.

Carers' perceptions of where consumers sought help following suicidal behaviours and consumers' reports of where they sought help from following self-harming, showed a clear difference to each other, with carers reporting highest use of hospitals (86.7% - n=26 of 30 respondents) and consumers reporting highest use of GPs (48.3%, n=42 of 87 respondents). Despite problems in consistency of question structure across the carer and consumer surveys further exploration of these differences is warranted. Non-disclosure of the extent of self-harming or suicidal behaviour by consumers to their carers may be an issue here.

Carers were less likely to seek help from psychiatrists (15.9% - n=7 of 44) and more likely to seek help from staff at the hospital emergency department (29.5%, n=13 of 44). This may reflect the limited communication that many carers have with the psychiatrist who sees the person they care for. It may also reflect hospital emergency departments as being the only perceived option for many carers.

Similar to consumers' experience, more than a third of carers (35.9%, n=14 from 39 respondents) did not get a response from services when they requested support when consumers were suicidal or self-harming and 66.7% (n=26) waited for 2 days or more (with more than half of these not getting a response). This was

despite two thirds of carers reporting that the consumer needed medical attention at these times with this involving hospital emergency department contact at the time, as reported by 86.7% of carers, with the remainder attending a GP.

In 76.5% of cases (n=26 of 34), carers reported that the person they cared for was referred to a mental health professional as a result of the self-harming at these times. The remainder were not, and it is unclear whether this was a single contact or ongoing support.

Of 67 respondents, community supports were perceived as neither very helpful nor very unhelpful. The most significant pattern across the responses was that these services were perceived by carers to be either not used or not applicable for the person they cared for. This was particularly so for gambling support (96.8%), men's shelters (93.5%), youth shelters ((84.7%) and women's shelters (82.8%). This is of much concern given the needs of people with BPD and high rates of homelessness and lack of family and friendship support among this population.

At the conclusion of this carer survey, respondents who completed all questions were asked if they wished to make any further comments. The following carer's comment captures some of the many issues described in this report.

*'It has been a long hard road we have both been on - now at the age of 36 she has been given less than 2 years to live as she has liver disease. I guess I always knew she would not live a long life but I never thought it would end like this. The medical profession have put us through sheer hell and it's now time they realised this disorder is very real and respond accordingly.'*

## Introduction

Though people with mental illness often experience stigma, consumers with diagnoses of borderline personality disorder (BPD) have traditionally endured not only societal stigma but extreme levels of exclusion and disapproval from within psychiatric services themselves. Families have had to fight for services, even for family members in crisis, and there is a great deal of confusion about treatment efficacy.

It is rare in the literature of mental health research to find studies from the perspectives of people with this debilitating condition, and from their family members: there is a lack of information about what a diagnosis of BPD has meant for them, the treatment consumers may or may not have received, the barriers to care people experience, and their perceptions of the quality of services received. It is far more common, particularly in the last two decades, to find research about various forms of individual and group psychotherapies and treatment protocols. This growth of research about BPD treatment is partly because traditional approaches have been described as "woefully inadequate" (Linehan, 1993, p. 3), together with an acknowledgment that people with this diagnosis who seek help account for a substantial number of inpatient and outpatient services used.

We know that a diagnosis of BPD is contested territory at a number of levels. The use of the adjective "borderline" to describe a large sub-set of people with personality disorders (PD), the use of the term "PD" as a derogatory label, and the definition of BPD itself, have been subjects of ongoing dispute. The disorder has only recently been formally recognised as a discrete diagnosis and viewed as a mental health service

responsibility to treat. There is academic argument about whether associated issues of emotional regulation can be conceptually understood as a form of post-traumatic stress disorder (PTSD).

As suggested above, it has long been acknowledged that people with a diagnosis of BPD may be viewed with negativity by some mental health service providers. Their issues and needs seem chronic and unrelenting, and their emotional pain unassuageable. At the same time, because difficulty with relationships of trust is at the core of the experience of BPD, service providers need high levels of skills and training to effectively engage with people. Consumers who are refused care or derided for needlessly taking up valuable resources are further traumatised. These factors impact on their family and carers.

The evidence base for treatment efficacy has been relatively poor. There is controversy about the use of medication, and the evidence for a physiological component is as yet in the early stages of research. It is not surprising therefore, in an environment of treatment uncertainty and negative experience of services that consumers and their families continue to struggle to access effective assistance. This Report offers unique information contributing to the growing body of work aimed at improving treatment and services, from the points of view of consumers with diagnoses of BPD and their families.

## Background

The following presents a brief background discussion of the symptoms and behaviours that attract a diagnosis of BPD, issues of prevalence, co-morbidity, health utilisation and treatment.

## BPD Definition and Diagnosis

Borderline Personality Disorder is considered a type of personality disorder. Five of the following criteria need to be present for diagnosis under the American Diagnostic System of Classification (DSM) IV:

- Frantic efforts to avoid real or perceived abandonment;
- A pattern of unstable and intense interpersonal relationships, characterized by alternating between idealization and devaluation ("love-hate" relationships);
- Extreme, persistently unstable self-image and sense of self;
- Impulsive behaviour in at least two areas (such as spending, sex, substance abuse, reckless driving, binge eating);
- Recurrent suicidal behaviour, gestures, or threats, or recurring acts of self-mutilation (such as cutting or burning oneself);
- unstable mood caused by brief but intense episodes of depression, irritability, or anxiety;
- chronic feelings of emptiness;
- inappropriate and intense anger, or difficulty controlling anger displayed through temper outbursts, physical fights, and/or sarcasm;

- stress-related paranoia that passes fairly quickly and/or severe dissociative symptoms— feeling disconnected from one's self, as if one is an observer of one's own actions (American Psychiatric Association, 1994, p. 654).

The DSM-IV places personality disorders on a separate axis (Axis II) from other mental disorders (Axis I), grouping them into Clusters. Borderline Personality Disorder is considered a Cluster B personality disorder, “dramatic, emotional or erratic” (DSM-IV code 301.83).

The International Classification of Diseases (ICD -10), a European system, defines BPD as: “characterized by a definite tendency to act impulsively and without consideration of the consequences; the mood is unpredictable and capricious. There is a liability to outbursts of emotion, and incapacity to control behavioural explosions. There is a tendency to quarrelsome behaviour and to conflicts with others, especially when impulsive acts are thwarted or censored.” People may experience marked mood instability, disturbances of self-image, rapid mood shifts, intense, unstable relationships and recurring impulsive self-harming behaviour (NICE, 2009). They may also feel a persistent lack of identity, a sense of emptiness, and engage in frantic efforts to avoid real or perceived abandonment. As with the DSM-IV, organic disease, injury or other psychiatric diagnosis are required to be excluded.

Both sets of criteria have been critiqued and are considered poorly validated. While there is classification criticism about the DSM system, there is little research about how doctors actually *use* it. Personality disorder itself is difficult to diagnose (Manning, 2000; Mulder, 1997), and applying these classifications in psychiatric practice is a matter of ongoing debate. Studies also suggest psychiatrists are ambivalent about making a BPD diagnosis (Brown, 1987; Whooley, 2010) because of the pervasive stigma both in society and from within psychiatric services. They may fear negative effects for the patient’s employment or insurance, and vary greatly in how they perceive and use DSM categories (Whooley, 2010).

## Prevalence and Factors Associated with BPD

Borderline Personality Disorder is considered the major form of personality disorder, both the most common and most serious (Chanen et al, 2007). There are differing United States (US) estimates of prevalence ranging from 0.7 to 4.6% of the general population (Swartz et al, 1990; Weissman, 1993; Samuels et al 2002; Coid, 2003; Crawford et al 2007). A conservative mid-range of approximately 2% may not seem very much, but people with BPD diagnoses make up about 20% of psychiatric inpatients and 10% of outpatients receiving services (Lieb et al, 2004). The 2% population estimate was challenged by the first large community study of personality disorders, which found a lifetime prevalence of 5.9%, with no significant difference in the rate of prevalence in men (5.6%) and women (6.2%) (Grant et al, 2008). The authors concluded that BPD is far more prevalent than previously recognized, equally prevalent among men and women, and is associated with considerable mental and physical disability. Importantly 5.9% is much higher than the lifetime prevalence of 0.4% for schizophrenia (Saha et al, 2005) and 1.4% for bipolar disorder (Kessler et al, 2005). Though there are cultural differences between the US and Australian populations, for example, in levels of unemployment,<sup>1</sup> socio-economic disadvantage, and availability of

<sup>1</sup> Current estimates US 9.1%, US Bureau of Labour Statistics, 2011; Aus. 5.3% ABS, 2011.

health care, this study indicates that the numbers of people whose lives are affected by BPD may be greater than previously recognised.

Most people (74%) diagnosed with BPD have at least one co-occurring Axis II disorder (Barrachina et al, 2011), and strong co-morbidity with Axis I conditions such as serious depressive episodes, and bipolar II disorder (Stone, 2006), making accurate assessment of prevalence difficult. Many databases of mental illness enter a primary diagnosis only, or at best primary and secondary. There is an association of Cluster B personality disorders, including BPD, for example, with major depressive disorders. In a 2001-2001 national US survey when 1,996 participants with major depressive disorder were interviewed three years later, the association with BPD was clearly demonstrated, leading the authors to recommend assessment for BPD in all patients with major depressive disorders (Skodol et al, 2011). People who meet criteria for BPD are more likely to experience substance abuse than people with other psychiatric disorders, except for Anti-Social Personality Disorder (ASPD) (McCann, Flynn and Gersh, 1992). They have high rates of suicide and suicide attempt, with up to one in ten people dying by completed suicide (Paris, 2002; NICE, 2009).

The gender of consumers with BPD remains contentious, with more young women diagnosed than men (Widiger and Weissman, 1991). No gender difference, however, is found in population studies (Lenzeweger, Loranger and Kessler, 2007; Torgersen, Kringlen and Cramer, 2001). Several studies have looked at gender differences in DSM personality disorders generally, some of which (Carter et al, 1999; Samuels et al 2002) found a gender difference, with Cluster B prevalence higher in *men* than in women. The United Kingdom (UK) Office for National Statistics (ONS) 2000 survey for psychiatric morbidity confirmed this finding, with lower rates of BPD in women than men (four per 1,000 compared with 10 per 1,000 in men) (Brazier et al, 2006).

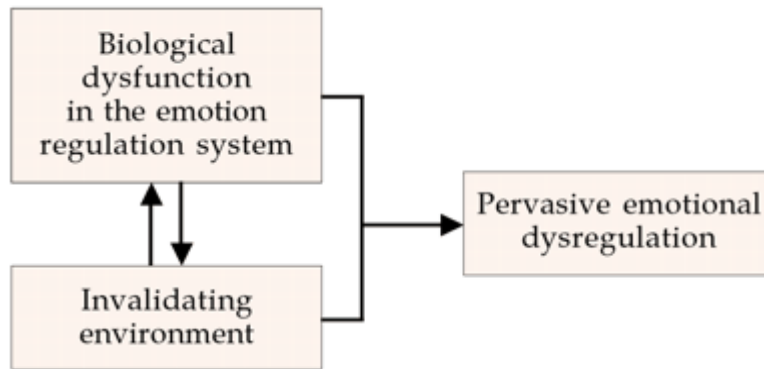
The association of personality disorders including BPD with childhood sexual or other abuse is clearly established (Johnson et al, 1999; Mullen, King and Tonge, 2000), but the clinical picture of adults with a history of childhood sexual abuse (CSA) is highly variable (Mullen, King and Tonge, 2000). Sexual abuse, especially in young children of eight years and under is a significant predictor of both BPD and PTSD whether or not the perpetrator is a family member. Nevertheless, having this sort of traumatic childhood experience is not a “pre-requisite” criterion for BPD, and a history of CSA is associated with a broad range of emotional and psychological disturbance (Mullen, King and Tonge, 2000).

There is limited research about cultural and socio-economic issues associated with personality disorders. Unemployment has been found to be positively related to BPD (Kessler and Merikangas, 2004). In the Baltimore Hopkins Epidemiology of Personality Disorder Study, Cluster B disorders were found to be most prevalent in people who had not graduated from high school (Samuels et al, 2002), and least prevalent in people who continued education after high school. The odds of having a Cluster B disorder declined by approximately 6%, for every additional year of age; that is, the older the person was the less likely he or she was to have diagnoses of BPD. A significantly higher prevalence of personality disorders has been noted in urban rather than rural communities (Amer and Molinari, 1994), and the prevalence is higher in places of concentrated social disadvantage such as prisons, boarding houses and slums (Mulder, 1997).

There is some evidence for a genetic component to BPD. In a large multinational twin study of community samples in Holland, Belgium and Australia, Distel et al (2008) found genetic influences explained 42% of the

variation in BPD features in both men and women, with the variability estimate being similar in all three countries. The relationship between symptoms, psychological mechanisms and neurobiology is unclear (Kernberg and Michels, 2009). Linehan (1993) suggests a Biosocial Theory of BPD essentially as a disorder of self-regulation. People with BPD are viewed as very volatile or unusual in temperament, compounded by repeated experiences of invalidation (Palmer, 2002).

### **Biosocial Theory of Borderline Personality Disorder** (From Palmer, 2002)



**Fig. 1 Biosocial theory of borderline personality disorder**

### **Use of Psychiatric Services**

Compared with psychiatric inpatients with other diagnoses, inpatients with BPD diagnoses have higher utilisation of mental health services over a range of indicators: in number of presentation times, length of hospital stay for mental health and or substance abuse, number of psychiatrists ever seen, and number of courses of psychotherapeutic treatment (Sansone, Songer and Miller, 2005).

It is difficult to accurately gauge the readmission rates of Australians with any form of mental illness, including people with a diagnosis of BPD. In the public system, it is suggested states and territories differ in their ability to track post-discharge follow-up between hospitals and community services, and or other hospitals. In a report of service utilisation and clinical status of patients with primary or secondary diagnosis of BPD admitted to *private* hospital-based psychiatric services based on data submitted to the Private Mental Health Alliance's (PMHA) Centralised Data Management Service (CDMS) the (ICD)-10 classification code "F60.31 Borderline Type" for patients' principal or any additional diagnosis was used as the basis for reported statistics. To be considered as a person with a BPD diagnosis, a person had one episode of overnight inpatient or same-day care (or separation) between 1<sup>st</sup> July 2009 and 30<sup>th</sup> June 2010. In that time-frame, 1, 847 persons with *any diagnosis of BPD* (approximately 7% of patients regardless of PD diagnosis) received psychiatric services at a rate per person of approximately 1.5 episodes of overnight inpatient care and 1.4 episodes of ambulatory care. Most were women (86%). The average length of stay (LOS) was approximately 18 days for episodes of overnight inpatient care and 12 days for episodes of ambulatory care.



The following section briefly describes BPD treatments discussed in the literature. The discussion is not exhaustive, a project beyond the scope of this Report, however the BPD NICE Guideline on Treatment and Management (2009) offer a thorough overview of the full range of therapies.

## Borderline Personality Disorder Treatment

It is only in the last two decades that a concerted effort has been applied internationally to provide effective treatment to people stigmatised as having incurable “attention-seeking” mental health issues, dispelling the myth of BPD as untreatable. Treatments often combine psychotherapy and medication, though there is controversy about the over-use of medications.

Studies of clinical trials are difficult to assess on a number of levels. Few use control groups for comparison of the effect of interventions. Randomised trials are almost always run in short times-frames of 12 months or 18 months, in contrast to the clinical view that long term treatments are essential (Kernberg and Michels, 2009). There is a great deal of difference in the way populations are defined. The co-occurrence of other personality and Axis I disorders discussed above, together with needing five of the nine operational criteria present for diagnosis, make for a degree of variation in the people who take part in trials (NICE, 2009). Psychological interventions are typically delivered by psychiatrists, psychologists and mental health nurses with extensive experience and training in treating people with BPD, making it hard to assess treatment models independently from the effect of those delivering them. Studies use different outcomes measures that may not apply to all people with BPD, such as rates of self-harming behaviour, hostility and impulsivity (NICE, 2009). Lastly, trials run by the proponents of particular therapies are more likely to have positive findings than those independently run, irrespective of the rigour of methodology (Luborsky et al, 1999).

Psychotherapy for people with diagnoses of BPD has been described in three main categories: psycho-analytically oriented, cognitive behavioural and supportive. In practice, therapists use different strategies borrowed from all three of these approaches.

Psycho-analytical models are based on the theory that unconscious conflicts underpin the extreme swings of temperament and behaviour experienced by people with diagnoses of BPD. Psychic “integration” is sought through careful review of the person’s radically divergent attitudes (Stone, 2006). In the process the emotions people feel about important early figures such as parents, are theoretically attributed or transferred to the therapist, the concept of “transference.” The therapist then uses these emotional attributions to raise awareness in the person about his or her inner conflicts. Kernberg, Clarkin and Yeoman’s (2002) transference-focussed therapy (TFP), Young’s schema-based therapy and Bateman and Fonagy’s mentalization-based therapy (MBT, 2004; 2006) are some examples.

Cognitive behavioural approaches focus on observable behaviours and patterns of thought with the aim of reducing “all or nothing” ways of seeing the world, improving emotional regulation and increasing feelings of self-worth and identity. Their efficacy is most clearly demonstrated in Linehan’s Dialectical Behaviour Therapy (DBT) (1993), which has gained momentum internationally. DBT treatment combines validation techniques and problem solving strategies and is conducted principally in groups. A key concept of DBT is the Zen Buddhist notion of mindfulness, teaching people to be somewhat detached and observing of their

experiences, rather than feeling overwhelmed by them, and therefore having more mastery of them (Palmer, 2002).

Supportive therapies emphasise a therapeutically empathic attitude to a person's sense of being very alone. An example is interpersonal therapy (IPT), a time-limited structured supportive therapy first developed for people with major depressive illness.

The use of pharmaceuticals with people with diagnoses of BPD remains a matter of much discussion. The National Institute for Health and Clinical Excellence (NICE) clinical guideline specifically recommends against any drug treatment for people with diagnoses of BPD, except for use in people with comorbid conditions. The guidelines concede there is some evidence that drug treatments can reduce the severity of specific symptoms in the short term, but state that there is no evidence that they alter the fundamental nature of the disorder in the short or longer term.

## Survey Method

These surveys were developed as online tools open to any Australian mental health consumer with a diagnosis of BPD, or any carer or family member of consumers with a diagnosis of BPD. The survey was part of a scoping exercise of BPD consumer and carer perspectives undertaken by Ms Janne McMahon OAM, Independent Chair of the Private Mental Health Consumer Carer Network (Australia) [Network], in consultation with BPD consumers, carers, research academics and members of the national government's BPD Expert Reference Group. The purpose was to better understand the needs of consumers with BPD diagnoses and of their family members and carers, what supports were most helpful and what barriers there were to accessing help in the current mental health system.

The survey instrument and questions were devised in the first instance by the Network Independent Chair, and then reviewed by consumer, carer and academic researcher stakeholders. To be able to compare Australian and American data later about parents' experiences of children and adolescents with BPD, six questions were drawn from BPD online surveys of 2010 and 2011 that were run by the National Education Alliance for Borderline Personality Disorder in the United States of America (USA). These American surveys were offered to parents about their offspring with diagnoses of BPD, and conducted by Dr. Marianna Goodman MD et al (Goodman et al, 2010). Piloting the Australian BPD surveys was not possible due to time constraints.

Participation in the BPD carer survey was open to any carer who identified themselves as being a person whose family member had a diagnosis of BPD and were those that responded to an invitation to participate distributed in the first instance to 20 mental health service organisations and 29 consumer and carer networks across Australia, including clinical mental health service systems and community and non-government organisations with a request for on-forwarding to consumers and carers. The surveys were widely publicised and delivered online via 'Survey Monkey' across Australia. The surveys were conducted between 27<sup>th</sup> May and 30<sup>th</sup> June 2011. It should be noted therefore that since the survey respondents were not a random sample from a population based sampling frame of BPD consumers, and were instead self-selected by virtue of choosing to participate in the survey, the extent to which the conclusions drawn from the survey are representative of the wider BPD population depends on the extent to which response bias

may have existed. Similarly, many consumers that did participate were also selective of which questions they would answer, particularly later in the survey.

## **Statistical analysis**

The data are presented predominantly as descriptive statistics. Univariate analysis using the Statistical analysis was performed using either the “Survey Monkey” cross-tabulation function within the online survey or STATA statistical software version 12.1 (StataCorp, Texas). Comparisons of survey proportions with known population percentages were compared using a one-sample test of proportions. Chi-square tests of association were performed in order to identify relationships between categorical variables. Fisher’s exact tests were used for categorical variables with low or zero cell counts. Cramer’s V effect size was also used to assess effect size. This statistic ranges from 0 to an upper limit of 1 where conventional criteria are 0.10 = small, 0.30 = medium, and 0.50 = strong. The statistic helps facilitate a meaningful interpretation of the strength of any relationship. The level of statistical significance was chosen as  $p < 0.05$ . Although a large number of hypotheses were tested, we did not adjust for the number of comparisons performed. Rather, we have left the p-values as they stand and interpreted the findings cautiously. The reader should be aware of this when reading the report. Confidence intervals for proportions are not presented since the results were not designed to estimate the views of the total Australian BPD population, but instead represent the views of those individuals with BPD and carers of individuals with BPD that responded to the survey.

## **Results**

### **Survey response rate**

There were 128 carers who took part in the online survey, however it is impossible to ascertain just how many carers the survey was on-forwarded to. This precludes the estimate of the response rate as well as obtaining details of who did not respond, i.e. age, geographic location etc.

## **Demographic Details**

### **State and Territory Location**

All 121 carers indicated the state or territory in which they lived. Survey responses were received from carers in each region of Australia, except the ACT and Northern Territory. The distribution of the responses received from consumers in each state was similar to the distribution of the national population. The higher response rates in SA, Victoria and WA may reflect more effective network dissemination of the survey through those states or may simply reflect the large sampling variation due to the relatively small number of participants in each State.

**Table One: Response Count by State or Territory (n=121)**

Australian State / Territory	Total Population	Percentage of total population	Survey response count	Percentage of survey population	One sample test of proportions (p-value)
New South Wales	7,238,819	32.4%	23	19.0%	0.17
Victoria	5,547,527	24.8%	33	27.2%	0.72
Queensland	4,516,361	20.2%	23	19.0%	0.88
Western Australia	2,296,411	10.3%	18	14.9%	0.49
South Australia	1,644,642	7.4%	19	15.7%	0.12
Tasmania	507,626	2.3%	5	4.1%	0.87
Australian Capital Territory	358,894	1.6%	0	0.0%	NA <sup>1</sup>
Northern Territory	229,675	1.0%	0	0.0%	NA <sup>1</sup>
<b>Total</b>	<b>22,340,905</b>	<b>100</b>	<b>121</b>	<b>100</b>	

<sup>1</sup>Insufficient observations

Source of national data: ABS (2011) 201.0 - Population by Age and Sex, Australian States and Territories, Jun 2010. <http://www.abs.gov.au/Ausstats/abs@.nsf/mf/3201.0>

### Location Density

Of the 121 respondents, all provided information on their area of residence. Approximately two thirds of survey respondents lived in Capital cities (62.0% - n=75) with 33.9% (n=41) living in regional towns and 4.1% (n=5) in remote towns in Australia. According to the Regional Institute, more than 82% of Australians live in Metropolitan centres and within 50kms of the coast. This suggests that either a disproportionately higher number of carers supporting a person with BPD live in regional centres (33.9% vs <12%, p<0.001) or that BPD carers living in regional areas were more likely to take part in this survey than their metropolitan BPD counterparts. This could be due to differences in levels of perceived support, isolation or other factors.

Source: The Regional Institute Ltd <http://www.regional.org.au/au/countrytowns/keynote/hugo.htm>

### Gender

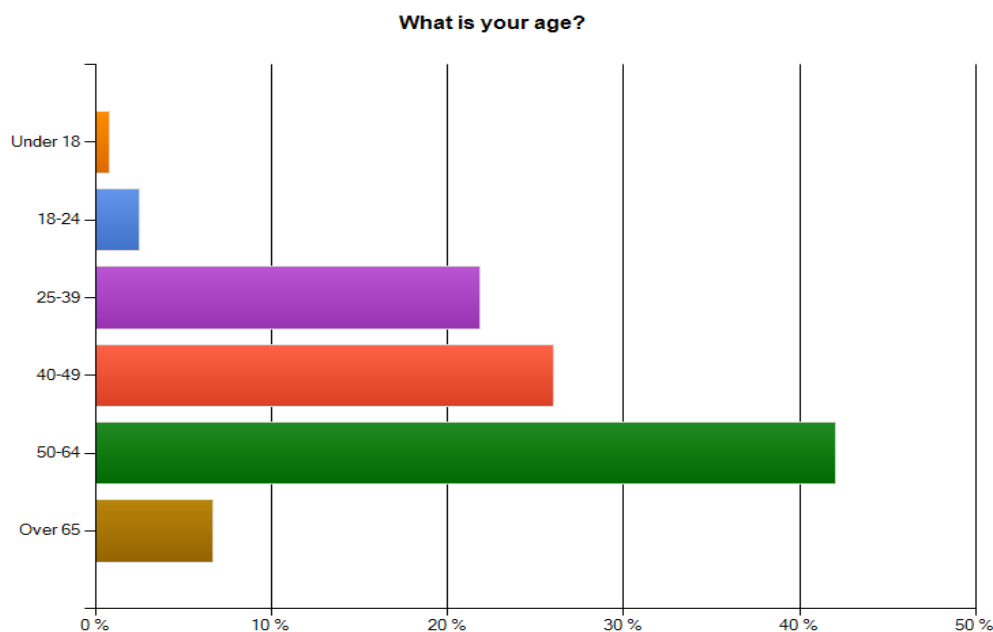
Of the 114 respondents who recorder their gender, most were female (79.8% - n=91) compared to males (20.2% - n=23). This does not reflect the national gender mix of 51% females and 49% males in the overall Australian population (p<0.001). This may either reflect the higher rates of women in carer roles or the possibility that more female carers chose to participate in this survey than male carers.

Source: ABS (2011) 201.0 - Population by Age and Sex, Australian States and Territories, Jun 2010. <http://www.abs.gov.au/Ausstats/abs@.nsf/mf/3201.0>

## Age

Of the 119 subjects who responded to this question, almost half were in the 50-65 years age group (42%-n=50) with the next highest concentration of carers in the 40-49 year age group (26.1% - n=31). Smaller figures were reported in other age groups (Figure 1). . The age range for carers for a person with BPD therefore included the whole adult lifespan but particularly includes those in the prime working decades from 25-65 years.

**Figure One: Age of Carers (n=119)**



## Marital status

Of the 117 subjects who responded to this question, almost two thirds were in a spouse/partner relationship (61.5% - n=72), a quarter were separated or divorced (25.5% - n=30), 12.8% (n=15) were single, and none were widowed. Given the age of the respondents and the national figure for marital status within the same age groups, this suggests that people caring for a person with BPD are more likely to be in a spouse/partner relationship compared to their age matched counterparts in the general population.

Source: Hayes A, Weston R, Qu L, Gray M. (2011) Families then and now: 1980-2010. Australian Government: Australian Institute of Family

Studies <http://www.aifs.gov.au/institute/pubs/factsheets/fs2010conf/fs2010conf.html>

We also assessed whether carers who are single better or worse off in terms of service support and found no significant association (Table 2).

**Table Two: Association between carers relationship status with support accessibility and options (n=76)\***

	Relationship status		$\chi^2$	<i>P</i>	Effect size
	Single	Spouse/partner			
<b>Support access</b>			2.66	0.264	0.19
Very challenging	17 (47.22)	19 (52.78)			
Challenging	8 (40)	12 (60)			
Neutral/not challenging/not applicable	5 (25)	15 (75)			
<b>Support options</b>			1.07	0.585	0.12
Very challenging	16 (42.11)	22 (57.89)			
Challenging	9 (45)	11 (55)			
Neutral/not challenging/not applicable	5 (29.41)	12 (70.59)			
<b>Service availability</b>			1.02	0.60	0.12
Very challenging	11 (36.67)	19 (63.33)			
Challenging	7 (50)	7 (50)			
Neutral/not challenging/not applicable	10 (34.48)	19 (65.52)			

\*Data are presented as number (percentage)

### Aboriginal or Torres Strait Islander Descent

Of the 117 subjects that responded to this question, only one percent (n=1, 0.9%) were of Aboriginal or Torres Strait Islander Descent and 116 (99.1%) were not. These percentages do not reflect the overall Australian population densities and the perceived wisdom that Aboriginal carers actually make up a disproportionately higher percentage of those in carer roles for persons with BPD than the non-aboriginal population. This perhaps suggests that a lower proportion of aboriginal carers participated in the survey than non-aboriginal carers and that other means of seeking the views of aboriginal carers may need to be explored.

Source: **S. Jenkins & F. Seith (2011) State Carers Policy: Background Paper on Aboriginal Carers. Adelaide: Human Services Reform Branch in the Department of Human Services/State Government of South Australia (Unpublished).** <http://www.sapo.org.au/pub/pub1642.html>

### Country of Birth, Years in Australia, and Language Spoken at Home

Twenty-nine respondents were born outside of Australia and came from a range of countries, including 11 from the UK, five from New Zealand, three from Singapore, two each from the Netherlands, South Africa and the USA, and one from each of the following countries: India, France, Tanzania, and Hungary. Though small in number, the variety of backgrounds suggests that the survey captured the views of people from diverse cultural backgrounds. Most of these respondents had been in Australia for 20 years or more, although nine had been in Australia for less than 10 years (one only for 2 months) and only three spoke a language other than English at home.

Eight carers indicated that the person cared for was also born outside of Australia (New Zealand, UK, USA and Singapore). The length of time that the carer had lived in Australia ranged from 6 months to 66 years, and none spoke a language other than English at home.

## **The Journey of Caring for a Person with BPD Diagnosis**

### **Status of the person cared for**

Of the 103 respondents who indicated their relationship to the person cared for, 30.1% (n=31) of the carers were a parent or guardian. Of interest, 24.3% (n=23) indicated that they were other than the survey defined relationships (Parent/guardian, spouse/partner, sibling, or son/daughter). These included being a foster parent, aunt, daughter-in-law or mother-in-law, and concerned community member. The other 18 respondents were paid health workers, either community support workers or professional clinicians who deemed themselves as a significant carer for the person. This suggests that some people with BPD have only these professional carers to support them, although there were no questions in the associated BPD consumer survey that could confirm this.

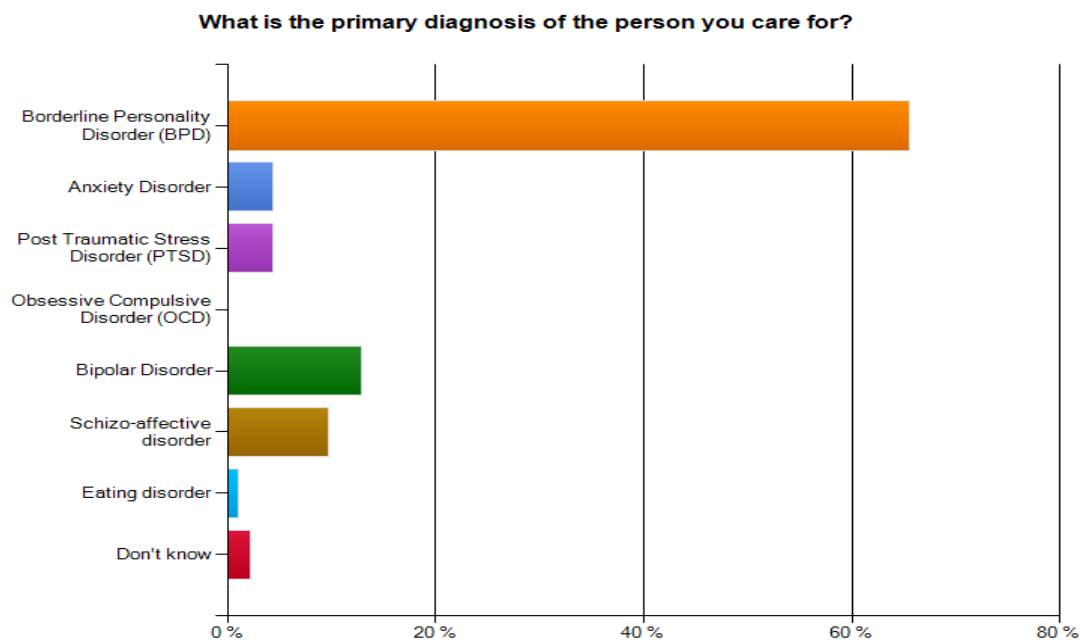
From 102 subject responses, the person cared for was more likely to be female (76.5% -n=78) than male (25.5% -n=24). This is not proportionate to the gender mix of the population (ABS 2011) or the evidence for the estimated BPD prevalence in the population (Grant et al, 2008). This finding suggests that either many men with BPD do not have carers or that a higher percentage of carers who care for women with BPD answered the survey. The person cared for was more likely to be single (51.0% - n=50) followed by a spouse/partner (28.6% - n=28), separated/divorced (17.3% - n=17) or widowed (3.1% - n=3). There was no survey question included in the consumer survey to determine whether the person lived with their carer. Therefore, aspects of the day-to-day contact with the person could not be examined.

Of 98 carer responses, only two indicated that the person they cared for was of Aboriginal or Torres Strait Islander descent.

### **Mental Health Diagnoses**

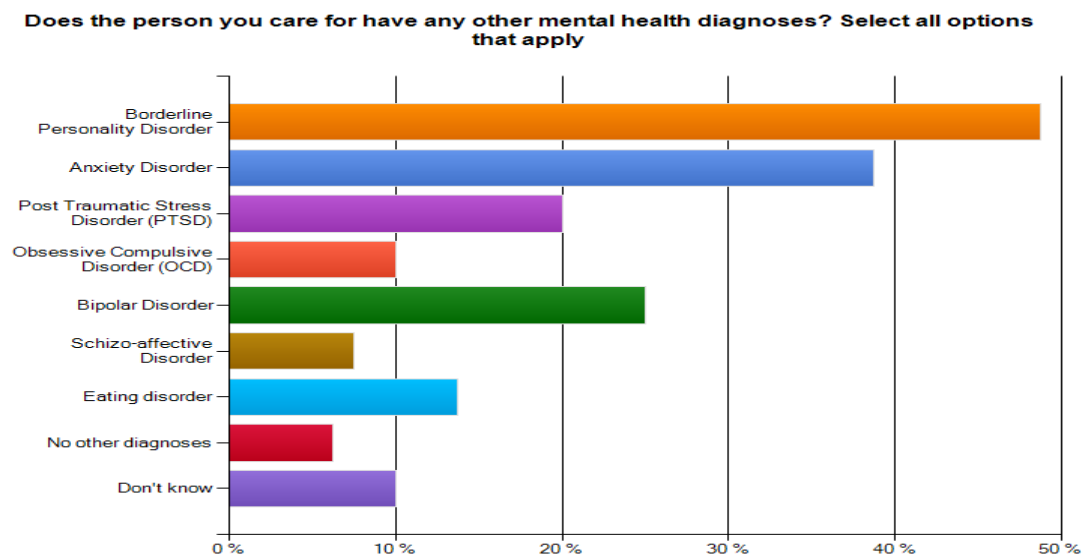
The primary diagnoses of the persons that 93 carers' cared for is shown in the following figure (Figure 2). Two thirds (65.5% - n=61) reported a primary diagnosis of BPD with far fewer indicating other primary diagnoses.

**Figure Two: Diagnosis of the Person Cared For (n=93)**



Of the eighty carer respondents to the question about the comorbidity, nearly half reported that the person they cared for had other secondary comorbid mental health diagnoses (48%, n=38) (Figure 3). Where a comorbid mental health diagnosis was the primary diagnosis, BPD was overwhelmingly reported as the secondary diagnosis. Anxiety Disorder was also prominent as a comorbid diagnosis (38%, n=30).

**Figure Three: Comorbid Diagnoses of the Person Cared For (n=80)**



The Carers' report of the diagnostic picture was quite different to that reported by consumers in the consumer survey, particularly with regard to comorbid diagnoses (Table 3). Although the groups weren't matched carer/consumer samples, there were some interesting looking differences that we explored



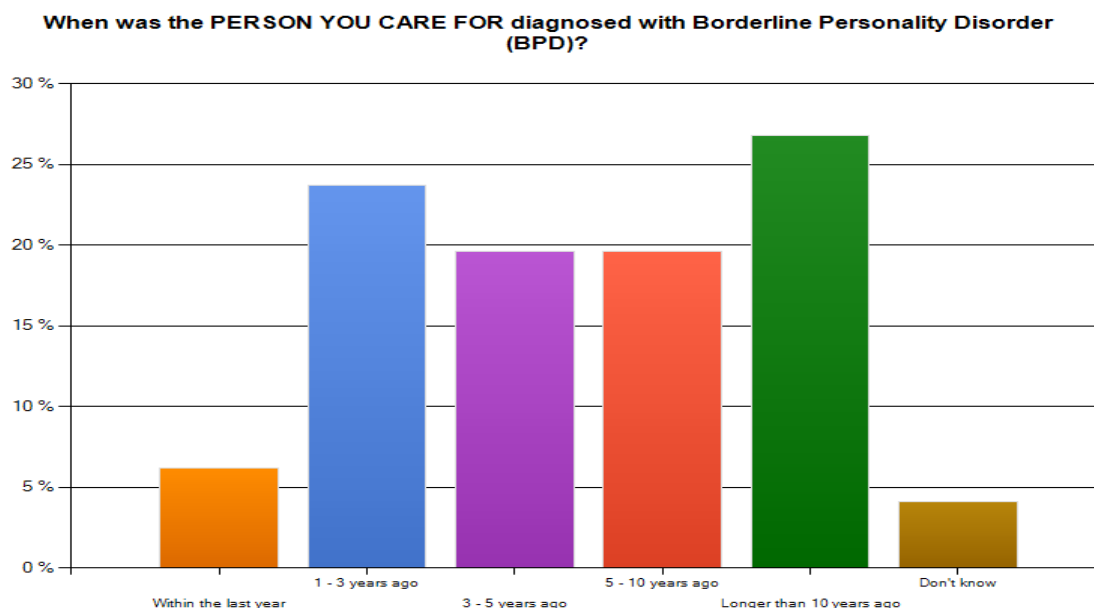
further. Bipolar Disorder was marginally higher in the carers' report of the consumers' comorbid diagnoses (25.0%, n=20 vs 14.5%, n=17; p=0.06), while BPD (64.1%, n=75 vs 48.8%, n=39; p=0.03), Anxiety Disorder (54.7%, n=64, vs 38.8%, n=31; p=0.03) and PTSD (41.0%, n=48 vs 20.0%, n=16; p=0.002) were noticeably higher in the consumers' report of their comorbid diagnoses. This may reflect the range of consumers and carers that responded to the survey but may also possibly reflect the differing understandings of mental illness and their differing experiences of its impact.

**Table Three: Carer & Consumer report of Primary and Comorbid Diagnosis of the Person Cared For**

	<b>Carer Primary</b>	<b>Consumer Primary</b>	<b>Carer Comorbid Diagnoses</b>	<b>Consumer Comorbid Diagnoses</b>	<b>Carer vs consumer co-morbid difference (p-value)</b>
<b>Borderline Personality Disorder</b>	<b>65.6% (41)</b>	<b>71.5% (88)</b>	<b>48.8% (39)</b>	<b>64.1% (75)</b>	<b>-15.3% (p=0.03)</b>
<b>Anxiety Disorder</b>	4.3% (4)	5.7% (7)	<b>38.8% (31)</b>	<b>54.7% (64)</b>	<b>-16.0% (p=0.03)</b>
<b>Post Traumatic Stress Disorder (PTSD)</b>	4.3% (4)	7.3% (9)	<b>20.0% (16)</b>	<b>41.0% (48)</b>	<b>-21.0% (p=0.002)</b>
<b>Obsessive Compulsive Disorder (OCD)</b>	0% (0)	0% (0)	10.0% (8)	13.7 (16)	-3.7% (p=0.44)
<b>Bipolar Disorder</b>	12.9% (12)	13.8% (17)	<b>25.0% (20)</b>	<b>14.5% (17)</b>	<b>10.5% (p=0.06)</b>
<b>Schizo-affective Disorder</b>	9.7% (9)	0% (0)	7.5% (6)	2.6% (3)	4.9% (p=0.10)
<b>Eating disorder</b>	1% (1)	1.6% (2)	13.8% (11)	13.7 (16)	0.1% (p=0.99)
<b>Don't know</b>	2.2% (2)	Not collected	<b>10.0% (8)</b>	2.6% (3)	7.4% (p=0.03)

The length of time since the person cared for was diagnosed was variable according to the 97 carers who answered this question, and it reflected a broad range of experience of caring, from those who had been diagnosed within the last year (6.2% - n=6), to those who had been diagnosed more than 10 years ago (26.8% - n=26).

**Figure Four: When the Cared for Person was First Diagnosed (n=97)**



Of carers who responded to which health professional made the first diagnosis of your cared for person (n=87), in most cases, a psychiatrist was the first to make a diagnosis (80.5% - n=70), with psychologists (9.2% - n=8) and GPs (6.9% - n=6) making the first diagnosis in far fewer cases. Only two carers didn't know who made the diagnosis. Eight carers stated the diagnosis was made by others, including a paediatrician in two cases, youth counsellors and inpatient teams.

Of concern, of 93 respondents, 62.4% (n=58) of carers reported that the medical professionals who diagnosed BPD did not explain to them as a carer what BPD means. A further 5.4% (n=5) had BPD explained but reported that they did not understand the explanation given. That is, only one third (32.3% - n=30) of carers had the diagnoses explained to them and also understood the explanation given. Thirty-two carers took the time to make further comments and most emphasised the struggle to get a clear diagnosis and be acknowledged and involved as carers.

*'Many different paediatric specialists were seen when she was a child/young teenager. All were concerned about her behaviour but variable in their assessment of causes, diagnosis and treatment.'*

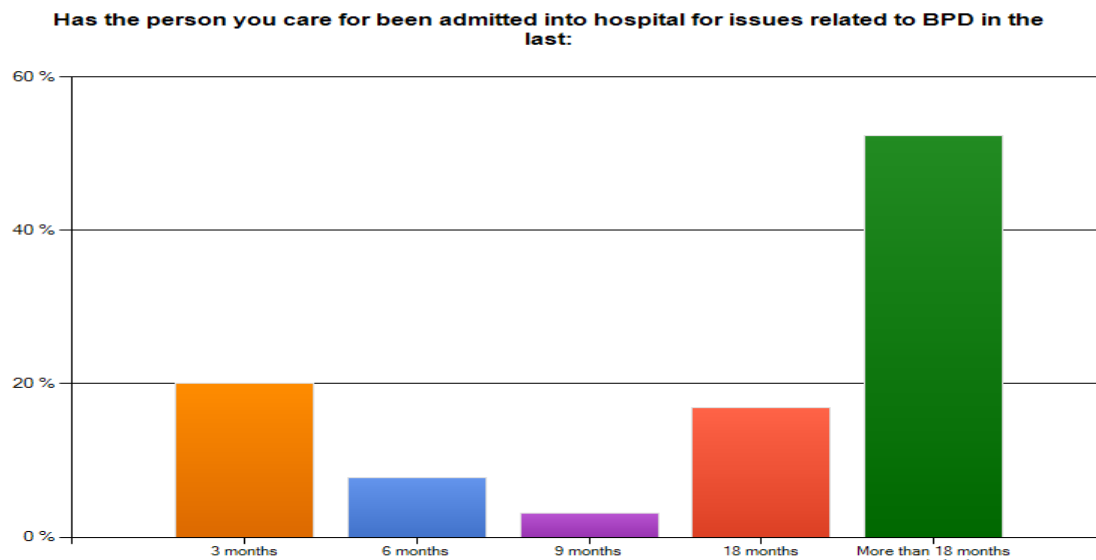
*'It took us about 4 years to finally get a diagnosis for our daughter. It was not until we found a great psychiatrist in the private system, that we were given a clear diagnosis and the information and understanding of what our daughter was suffering from. Up until this time, she had had many episodes of trauma, self harm and suicide attempts, and hospitalisations. We found that the public health system was TOTALLY incapable of helping her or us over this time.'*

*'I would have liked to be involved in the diagnosis process and been given a clear explanation and understanding about the condition. Instead I felt ostracised. Even the diagnosis given to the patient was said with no compassion or diplomacy, just sheer arrogance from the psychiatrist.'*

Patterns of hospital use, by the person with BPD, were reported by 65 carers, with more than half (52.3% (n=34) reporting that the person had either not been admitted to hospital or that it had been more than 18

months since their last admission (Figure 5). Of note however, 20% (n=13) of carers reported admission in the past 3 months, indicating that a range of carer experiences had been captured by the survey, including those experiencing acute BPD crises, involving hospitalization.

**Figure Five: Hospital Admissions for BPD (n=65)**



## Medication

According to the 94 carers who answered questions about the cared for person's medication, almost two thirds reported them taking anti-depressants for their mental health issues (61.7% - n=58), 46.8% (n=44) were taking an anti-psychotic medication, 28.7% (n=27) were taking an anti-anxiety medication, 22.3% (21) reported them taking no medications (this being similar to the 17.2% reported by consumers), and 5.3% (n=5) did not know what medication the person was taking (again this was similar to the 1.6% reported by consumers). The question did not allow respondents to indicate whether they were aware of consumers taking more than one of these types of medication and we can therefore only assume that carers nominated the primary medication. Responses from the 14 carer respondents who did not know their medication type but provided the medication names indicated that most patients were taking a combination of anti-psychotic medications and anti-depressants.

## Carers' Reflections on the Consumer's Experiences in Childhood and Adolescence

On reflection, the most common unusual behaviour or sign of future problems with mental health that carers noticed about the consumer during infancy or toddlerhood was sensitivity which was report by 57.9% (n=11) of the 19 carers who responded to this question (Table 4). Moodiness (42.1% (n=8), excessive separation anxiety (42.1% (n=8) and social delay (36.8% (n=7) were also highlighted. One carer gave further information stressing the presence of routine domestic violence in the infant's life. The small sample makes any definite conclusions difficult, though the identified issues highlight an area worthy of further exploration.

**Table Four: Issues Noticed in Infancy and Toddlerhood amongst carers (n=19)**

Issue	Response percent	Response count	Issue	Response percent	Response count
sensitivity	57.9%	11	inability to self-soothe	21.1%	4
moodiness	42.1%	8	physical abuse (of this child)	15.8%	3
excessive separation anxiety	42.1%	8	sexual abuse (of this child)	15.8%	3
social delay	36.8%	7	cognitive delay	15.8%	3
verbal delay	26.3%	5	motor delay	15.8%	3
picky eating	26.3%	5	colic	15.8%	3
poor temperament	21.1%	4	sensory problems	5.3%	1
inability to be consoled	21.1%	4			

Carers also reflected on whether they noticed anything unusual in the person they cared for during their childhood (n=19) (Table 5). Again, sensitivity rated highly (63.2% - n=13), along with difficulty making friends (63.2% - n=13), school refusal/truancy (52.6% - n=10) and being a victim of bullying (47.4% - n=9). Again, the findings are based on small number of responses, but if these findings were to be confirmed in a larger study they would have multiple implications for how parents and schools respond.

**Table Five: Issues Noticed in Childhood amongst carers (n=19)**

Issue	Response percent	Response count	Issue	Response percent	Response count
sensitivity	63.2%	12	Anger	36.8%	7
difficulty making friends or few friends	63.2%	12	frequent lying or deception	31.6%	6
school refusal or truancy	52.6%	10	suspension or expulsion	31.6%	6
bully victim	47.4%	9	sexual abuse (of this child)	31.6%	6
moodiness	42.1%	8	learning disability or special education	26.3%	5
multiple schools	42.1%	8	poor temperament	26.3%	5
poor grades	42.1%	8	victim of rape	15.8%	3
conflict with authority figures	36.8%	7	physical abuse (of this child)	10.5%	2
impulsivity	36.8%	7	bully perpetrator	5.3%	1

Carers also reflected on whether they noticed anything unusual in the person they carer for during their adolescence (n=19) (Table 6). At this stage, anger was the most prominent issue that carers reported

noticing (68.4%, n=13), followed by moodiness (63.2% - n=12), impulsivity (57.9% - n=11), body image issues (52.6% - n=10) and sensitivity (52.6% - n=10). There were some inconsistencies across the childhood and adolescence survey that meant that further examination of some issues eg. school related concerns was not possible.

**Table Six: Issues Noticed in Adolescence amongst carers (n=19)**

Issue	Response percent	Response count	Issue	Response percent	Response count
<b>Anger</b>	<b>68.4%</b>	<b>13</b>	emptiness	31.6%	6
moodiness	63.2%	12	property destruction	31.6%	6
impulsivity	57.9%	11	theft	26.3%	5
body image issues	52.6%	10	arrests	26.3%	5
sensitivity	52.6%	10	paranoia	26.3%	5
odd thinking or perceptions	42.1%	8	delusions	21.1%	4
recklessness	42.1%	8	physical abuse (of this child)	10.5%	2
alcohol abuse	42.1%	8	anorexia	10.5%	2
substance abuse	42.1%	8	bulimia	10.5%	2
boredom	42.1%	8	hallucinations	10.5%	2
sexual abuse (of this child)	36.8%	7	homicidal ideation	5.3%	1
poor temperament	36.8%	7			

Further issues that carers noticed during the consumer's adolescence were elicited (n=16) (Table 7). Difficulty making friends was noted by 62.5% of carers (n=10), followed by promiscuity (56.3%, n=9) and verbally abusive outbursts (50% - n=8).

**Table Seven: Further Issues Noticed in Adolescence amongst carers (n=16)**

Issue	Response percent	Response count	Issue	Response percent	Response count
<b>difficulty making or few friends</b>	<b>62.5%</b>	<b>10</b>	aggression	37.5%	6
promiscuity	56.3%	9	rape victim	31.3%	5
verbally abusive outbursts	50.0%	8	fight	31.3%	5
frequent lying or deception	43.8%	7	pregnancy	25.0%	4
violence victim	37.5%	6	STDs	12.5%	2

Carers with a child sought an evaluation of their child's problems mainly as a result of concern about behaviour problems (70.6% - n=12 of 17 respondents) and mood disturbances (58.8% - n=10) (Table 8). Of note, doctor and teacher recommendation was not often the reason for seeking an evaluation (17.6% - n=3). This paints a picture of a young person rapidly losing control of their life and circumstances, and their parents increasingly impacted by multiple issues beyond that expected of childhood and adolescence, but with little outside professional recognition of the problems or support before diagnosis.

**Table Eight: Carer's reasons for Seeking Evaluation of their child (n=17)**

Issue	Response percent	Response count	Issue	Response percent	Response count
behavioural problems	70.6%	12	temper tantrums	23.5%	4
mood disturbances	58.8%	10	eating disorder	23.5%	4
anger problems	47.1%	8	doctor recommendation	17.6%	3
substance abuse	41.2%	7	teacher recommendation	17.6%	3
police intervention or legal issues	29.4%	5	promiscuity	11.8%	2
school refusal	29.4%	5			

Once an evaluation was undertaken, carers (n=17) reported that therapy was the main treatment recommended for the person they cared for (64.7% - n=11), followed by medication (58.8% - n=10). Only 17.6% (n=3) of carers reported that hospitalisation was recommended.

## The Journey of Receiving Support for BPD

### Impact of Mental Health Support Services on Carers – Seeking Support

Of the 78 carer respondents who reported their experience of challenges in their carer role, it appeared that they found all of the designated issues very challenging, with a lack of support options available to them the most commonly cited challenge (50.6% - n=39) (Table 9). Of the six carers who made further comments, their responses emphasised a perceived lack of information about and awareness of available support, as one carer's comment demonstrates:

*'I've never tried to access support because I didn't know it was possible.'*

**Table Nine: Challenges Faced by Carers (n=78)**

	Very challenging	Challenging	Neutral / Not Challenging	Not applicable	Response Count
Unable to access support as a carer	<b>47.4% (37)</b>	26.9% (21)	17.9% (14)	7.7% (6)	78
Lack of support options for me as a carer	<b>50.6% (39)</b>	27.3% (21)	14.3% (11)	7.8% (6)	77
Services not available in my local area	<b>42.7% (32)</b>	18.7% (14)	22.7% (17)	16.0% (12)	75
Financial cost of accessing services as a carer	<b>37.3% (28)</b>	29.3% (22)	18.7% (14)	14.7% (11)	75

Upon further questioning of the types of support that carers have accessed, the 81 carer responses demonstrated that some types of support were perceived to be more helpful than others (Table 10). These included education and information (average rating 3.43), mental health professional support (2.95) and counselling for them as carers (3.08), though no support types were rated as 'very helpful' overall (i.e. an average of >4). Interestingly, the helpfulness of support groups was quite mixed (Table 10). These results suggest that carers of people with BPD may need more individualised support than that currently offered.

**Table Ten: Perceived Helpfulness of Services Accessed for Support (n=81)**

	Very unhelpful	Unhelpful	Neutral	Helpful	Very helpful	N/A	Average Rating	Count
BPD Education information	7.8% (6)	13.0% (10)	15.6% (12)	<b>37.7% (29)</b>	14.3% (11)	11.7% (9)	3.43	77
Support from my GP	10.7% (8)	16.0% (12)	<b>22.7% (17)</b>	17.3% (13)	14.7% (11)	18.7% (14)	3.11	75
Support from other MHPs	20.3% (16)	17.7% (14)	16.5% (13)	<b>27.8% (22)</b>	12.7% (10)	5.1% (4)	2.95	79
Counselling for me as a carer	15.6% (12)	11.7% (9)	18.2% (14)	<b>23.4% (18)</b>	13.0% (10)	18.2% (14)	3.08	77
Carer support groups	13.2% (10)	2.6% (2)	17.1% (13)	19.7% (15)	17.1% (13)	<b>30.3% (23)</b>	3.36	76

More than half of the 77 carers (62.3% - n=48) who responded to further questions about support stated that they had wanted to access support but had not been able to (Table 11). A small number of carers made further comments (n=11) with three noting the helpfulness of internet support and resources. Other comments help in understanding some of the above responses.

'Carer support groups originally helped (attending court, dealing with police etc.); now they just make me sad - there is no 'fix' to the problem from a parent's standpoint.'

Seventy-eight carers gave further insights into what had prevented them from being supported as carers of someone with BPD, with significant ratings across all of the domains listed in Table 11. Similar to consumers with BPD, being unable to access supports when needed (62.3%, n=48) and not being taken seriously rated (60.5%, n=46) high on the list of barriers experienced by carers:

**Table Eleven: Issues that have prevented carers from being supported in their role (n=77)**

	Prevented	Neutral	Has not prevented	N/A	Response Count
Unable to access support when needed	62.3% (48)	16.9% (13)	14.3% (11)	6.5% (5)	77
Not being taken seriously	60.5% (46)	23.7% (18)	10.5% (8)	5.3% (4)	76
Cost of support services	38.2% (29)	28.9% (22)	9.2% (7)	23.7% (18)	76
Lack of carer support available	56.6% (43)	19.7% (15)	18.4% (14)	5.3% (4)	76

Twenty-four carers took the time to make further comments. The following extracts reflect their comments:

*'There was often the feeling that the mother was exaggerating information about the child's extreme behaviour, or that it must be due to bad parenting. Yet there was no neglect, abuse, violence or addictions in the family...Specialists were often sympathetic but seemed to be clueless about what to actually do about the problems. A common feeling was that this family was "put into the too-hard basket".'*

*'My son has never sought help. I don't know what to do.'*

*'The time and anxiety around trying to gain access to support for myself has been extremely taxing in its own right. Time spent researching and trying to make sense of the different services and what, if anything, they can do to help. It never ends.'*

*'After my daughter slashed her wrists, she then hid the damage till the next day. I took her to the GP to have stitches: The GP said, "I've seen worse". That hurt. My daughter said she saw it as a challenge to do away with herself. It was awful.'*

*'The public health system was totally inadequate in giving us the help or care that we needed and the intensive care that our daughter needed. It was in fact very obstructive in guiding us toward effective help. We were told that our daughter would not be able to access help other than what she was getting in the public health system because of some of the aspects of her illness.'*

### **Impact of Mental Health Support Services for the Person Cared For**

Similar to consumers with BPD, carers (n=70) rated as challenging, the full range of listed issues that may cause anxiety for the person they care for. Of these, lack of choice of support services (58.2% - n=39), being unable to access supports when needed (56.7% - n=38) and lack of long-term consistent support (55.1% -



n=38) were rated as being very challenging more often than they were not (Table 12). Of note, when combining 'very challenging' and 'challenging' scores, not being taken seriously (88.2% - n=60) stood out as one of the biggest challenges carers perceived for the person they cared for. These results suggest that carers have a very good understanding of the struggles the person with BPD faces when attempting to get support.

**Table Twelve: Carers' Perceptions of the Hardest/Most Challenging Aspects for the Person Cared For (n=70)**

	<b>Very challenging</b>	<b>Challenging</b>	<b>Neutral</b>	<b>Not challenging</b>	<b>N/A not an issue</b>	<b>Count</b>
<b>Fear of losing MH support</b>	<b>40.6% (28)</b>	18.8% (13)	14.5% (10)	8.7% (6)	17.4% (12)	69
<b>Fear of losing long term therapist</b>	<b>39.1% (27)</b>	21.7% (15)	13.0% (9)	5.8% (4)	20.3% (14)	69
<b>Lack of long term / consistent support</b>	<b>55.1% (38)</b>	27.5% (19)	4.3% (3)	4.3% (3)	8.7% (6)	69
<b>Discrimination because of BPD diagnosis</b>	<b>52.9% (36)</b>	25.0% (17)	11.8% (8)	2.9% (2)	7.4% (5)	68
<b>Not being taken seriously</b>	<b>44.1% (30)</b>	<b>44.1% (30)</b>	7.4% (5)	1.5% (1)	2.9% (2)	68
<b>Being treated badly</b>	<b>41.2% (28)</b>	33.8% (23)	11.8% (8)	4.4% (3)	8.8% (6)	68
<b>Not feeling respected</b>	<b>51.5% (34)</b>	33.3% (22)	4.5% (3)	3.0% (2)	7.6% (5)	66
<b>Unable to access support when needed</b>	<b>56.7% (38)</b>	23.9% (16)	10.4% (7)	1.5% (1)	7.5% (5)	67
<b>Lack of choice of support services</b>	<b>58.2% (39)</b>	22.4% (15)	6.0% (4)	4.5% (3)	9.0% (6)	67
<b>Long waiting lists / times to see MH professionals</b>	<b>47.7% (31)</b>	23.1% (15)	9.2% (6)	6.2% (4)	13.8% (9)	65
<b>Services not available in our local area</b>	<b>38.5% (25)</b>	20.0% (13)	20.0% (13)	1.5% (1)	20.0% (13)	65
<b>Financial cost of accessing services</b>	<b>43.9% (29)</b>	18.2% (12)	10.6% (7)	4.5% (3)	22.7% (15)	66

Similar to consumers, when asked about which mental health services had been helpful /supportive for the person cared for, more of the total sample of carers (n=73) rated psychotherapy as being either helpful or very helpful (43.1%, n=31) compared with other services (Table 13). Identifying early warning signs, developing a crisis plan and hospital admissions stood out as very unhelpful (25.4%, 28.6% and 23.9% respectively) across the spectrum of service ratings. Many services were rated as not applicable by many carers, suggesting that they were not accessed at all. Similarly to consumers, DBT results were mixed although 40.5% found CBT either helpful or very helpful. Likewise, hypnotherapy was rated as the least helpful as most of the respondents rated this as not applicable suggesting the service was not often utilised.

**Table Thirteen: How Helpful/Supportive are Mental Health Services According to Type of Service? (n=68-71)**

	Very un helpful	Un helpful	Neutral	Helpful	Very helpful	N/A	Rating Average	Count
Identifying early warning signs	<b>25.4% (18)</b>	16.9% (12)	11.3% (8)	16.9% (12)	8.5% (6)	21.1% (15)	2.57	71
Developing a crisis plan	<b>28.6% (20)</b>	12.9% (9)	10.0% (7)	21.4% (15)	4.3% (3)	22.9% (16)	2.48	70
Education and information about BPD	14.1% (10)	<b>22.5% (16)</b>	18.3% (13)	15.5% (11)	12.7% (9)	16.9% (12)	2.88	71
Meditation	5.6% (4)	9.9% (7)	14.1% (10)	14.1% (10)	8.5% (6)	<b>47.9% (34)</b>	3.19	71
Hypnotherapy	4.3% (3)	5.7% (4)	8.6% (6)	4.3% (3)	1.4% (1)	<b>75.7% (53)</b>	2.71	70
Psychotherapy long term / regular therapist	12.7% (9)	9.9% (7)	11.3% (8)	<b>25.4% (18)</b>	<b>18.3% (13)</b>	22.5% (16)	3.35	71
Cognitive Behavioural Therapy (CBT)	7.2% (5)	10.1% (7)	11.6% (8)	<b>24.6% (17)</b>	<b>15.9% (11)</b>	<b>30.4% (21)</b>	3.46	69
DBT	8.3% (6)	8.3% (6)	6.9% (5)	12.5% (9)	12.5% (9)	<b>51.4% (37)</b>	3.26	72
Trauma Counselling	11.8% (8)	8.8% (6)	8.8% (6)	16.2% (11)	1.5% (1)	<b>52.9% (36)</b>	2.72	68
Hospital admission	<b>23.9% (17)</b>	18.3% (13)	7.0% (5)	21.1% (15)	7.0% (5)	22.5% (16)	2.60	71
MH support groups (dep'n, anger, PTSD, etc)	11.4% (8)	5.7% (4)	8.6% (6)	4.3% (3)	12.9% (9)	<b>57.1% (40)</b>	3.03	70
Community support groups (art, friendship)	8.6% (6)	5.7% (4)	11.4% (8)	14.3% (10)	14.3% (10)	<b>45.7% (32)</b>	3.37	70

More than half (52.2% - n=36) of carers (n=69) reported that the person cared for had wanted to access some of these services but had not been able to do so. Of these, 26 carers took the time to make further comments which give further understanding of the issues faced by the person with BPD when attempting to access these supports. Being refused access and being limited in what they could access were prominent in the responses, as well as the person not wanting to engage with supports.

*'Not been informed of any support services available.'*

*'As an adult, my niece is erratic in behaviour and has poor self-awareness. If she had been offered these services when a teenager she may have agreed and benefited, but in general she does not sustain effort and usually looks for ways to manipulate circumstances to her advantage. We wish we had had a chance to find out if any of these therapies could have helped her at the time.'*

*'She wanted access to these support services but she was not able to, not because she was refused access, but because of her own internal conflict in regards to being assertive enough to ask for help. Ideally, she wanted these support services to be "mind readers" and reach out to her so she doesn't have to reach out to them.'*

*'We were unable to access a Psychologist as we were told by Mental Health she gets enough support from DBT group.'*

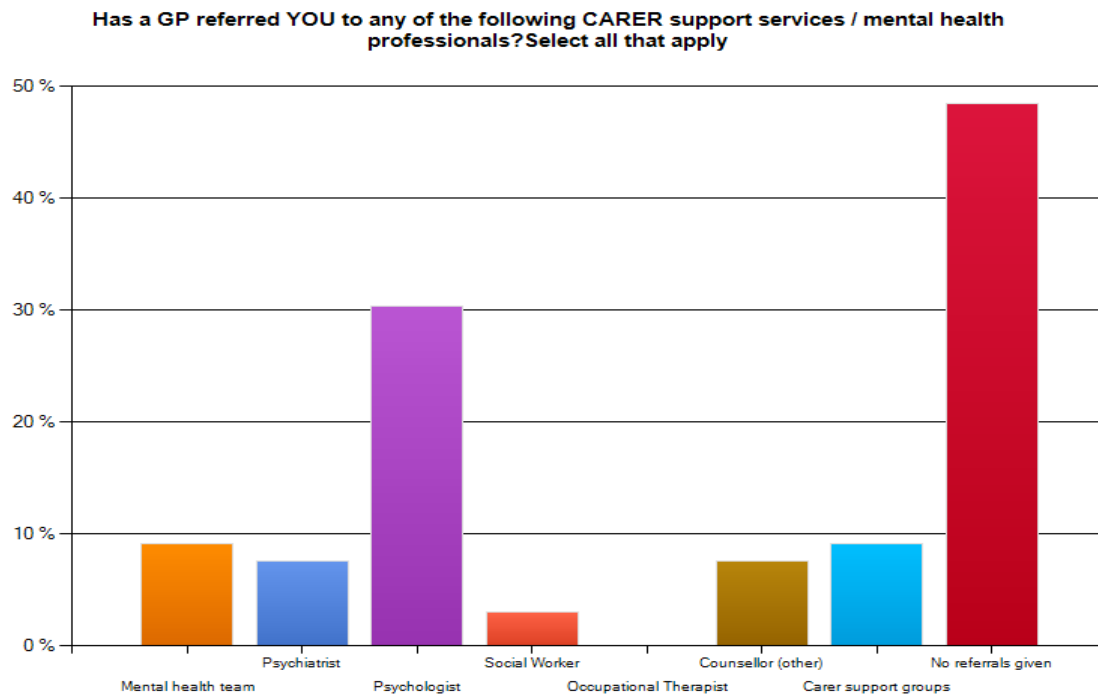
When asked which services have contributed most to support the recovery of the person cared for, 63 carers listed a range of support services and support types which are shown here in order of the most common (Several carers listed more than one support):

- 1) Psychologists (15)
- 2) Mental health teams (13)
- 3) Medications (12)
- 4) GPs (8)
- 5) Psychiatrists (7)
- 6) Community supports (6)
- 7) DBT groups (6)
- 8) Other groups (3)
- 9) Carers (2)
- 10) Alternative Diagnosis More Accepted (1)
- 11) Peer Support (1)
- 12) Friends (1)
- 13) School staff (1)
- 14) Hospital admission (1)

### **The GP Role in Supporting People with of BPD & Carers**

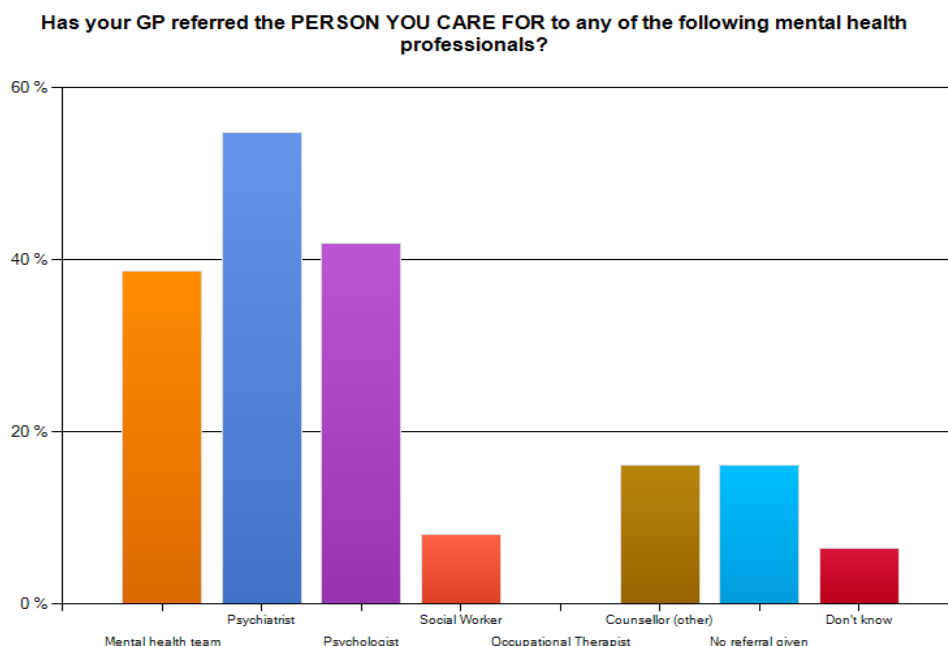
Of the 72 respondents to answer questions about GP support, 51.4% (n=37) said that their GP had not supported them as a carer. Of the 72, 76.1% (n=54) also reported that their GP does not provide them with personal counselling for issues related to being a carer. However 70.8% (n=51) reported that a GP has supported the person they care for in terms of issues related to BPD. Of those who indicated that they received this support (n=51), 37% (n=19) had been receiving support from their GP for less than six months. Referral of carers to carer support services or mental health professionals is reported as mixed, as shown in Figure 6. Of concern, almost half of carers (48.5% - n=32) reported that their GP had not referred them to other supports. Only two carers reported being referred to community carer support services (ARAFMI & Anglicare).

**Figure Six: GP Referral of Carers to Other Support Services (n=66)**



This was in contrast to the GP's that had made referrals for the person cared for to mental health professionals, as shown in figure 7. GPs appeared to be most likely to consistently refer carers and consumers with BPD to psychologists. This corresponds with carers ratings of psychologist as being among the most helpful mental health professionals in the provision of support to the person with BPD. It may also reflect system incentives and processes that GPs feel most comfortable and familiar with in their setting.

**Figure Seven: Carer Report of GP Referral of the Person with BPD to Other Mental Health Professionals**



(n=66)

Eighteen carers took the time to make further comments about GPs' support. The following demonstrate the range of responses, both positive and negative, with all indicating that GPs likely need more information and support to be effective in supporting carers and people with BPD:

*'Our GP has consistently supported our entire family in relation to our daughter's health and the impact it has had on the whole family. We feel that he could have had better access to more informative resources both locally and systemically.'*

*'I am the main disability advocate for my son. I request GPs to organise referrals/ visits to specialists if required otherwise I contact professionals myself and organise what is required.'*

*'GPs have been the most judgemental professionals that we have encountered. It has not been helpful or positive to share information and to garner support from GPs.'*

*'I think the GP has tried to help but again - it's the too hard basket.'*

*'The GP has provided no counselling or support. They diagnosed me with depression instead of listening to the situation, which was refuted, but I got a referral to a psychologist which was productive in the end. But they didn't take account of the impact of being a carer of someone with BPD, and only wanted to prescribe anti-depressants - all in a 5 min consult!'*

### Comparing GP Support across the Sector

As part of our further examination of the data, we asked "Are GPs doing a better job of supporting carers in the metropolitan or regional areas?" and "Do carers of consumers who use private hospitals have a different experience with GP support?"

The level of carer's perceived support provided by GP's was not significantly associated with geographical region (Table 14). There was however a significant association ( $p=0.037$ ) with medium effect size ( $V=0.33$ ) between carers' experiences with GP support and consumers with a BPD diagnosis having had a private hospital admission (Table 13). For carers of individuals with BPD who had no private hospital admissions ( $n=15$ ), 65.2% reported minimal GP support compared to 31.2% for those with past private hospital admissions. Given the small sample size and the non-matched nature of the data this observed association needs to be treated with caution.

**Table14: Association between carers perceived GP support with geographical region and private hospital admissions for Consumers with diagnosis of Borderline Personality Disorder (BPD)\***

	GP support		$\chi^2$	<i>P</i>	Effect size
	Yes	No			
<b>Region</b>			0.08	0.780	0.03
Metropolitan	21 (50)	21 (50)			
Rural	14 (46.7)	16 (53.3)			
<b>Private hospital admissions</b>			4.36	0.037	0.33
Yes	11 (68.7)	5 (31.2)			
No	8 (34.8)	15 (65.2)			

\*Data are presented as number (percentage)

### The Role of Public Hospitals

Respondents appeared to be more variable in which questions they answered in this section of the survey, opting to answer some and not others in greater or lesser numbers (16-68 respondents).

Of the 68 respondents who reported the usage of hospital services, 50% ( $n=34$ ) said the person they cared for use only public, 4.4% ( $n=3$ ) use only private, 20.6% ( $n=14$ ) use mostly public and some private, and 22.1% ( $n=15$ ) use mostly private and some public hospital services, and 2.9% ( $n=2$ ) didn't know.

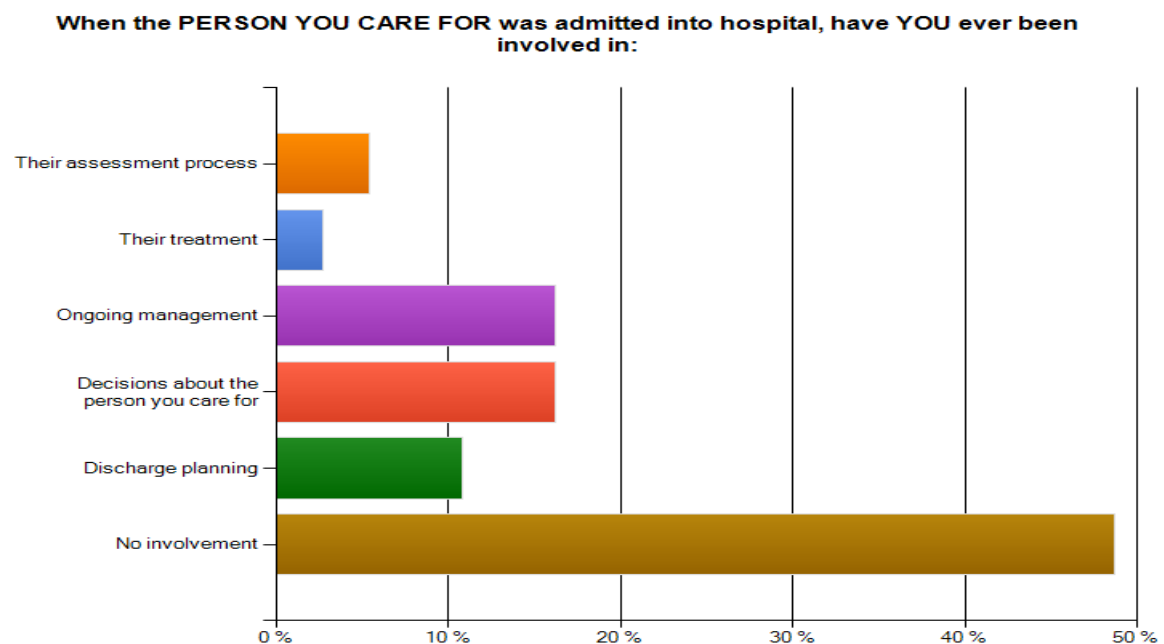
Of the 54 who responded to the question about the person they care for ever having been admitted to public hospital because of issues related to their BPD, 74.1% ( $n=40$ ) said 'yes' and 18.5% ( $n=10$ ) said 'no', and 7.4% ( $n=4$ ) didn't know. Of the 39 who responded to the question about the number of public hospital admissions in the past three years related to BPD, one third (33.3% -  $n=13$ ) reported that the person they care for had been admitted five or more times and 20.5% ( $n=8$ ) reported three admissions. In contrast, 23.1% ( $n=9$ ) had not been admitted during the past three years. None had never been admitted, and 20.4% ( $n=8$ ) had been admitted once only. Because questions about admission were asked differently to that contained in the consumer BPD survey, these results did not allow for the reporting of cases where the person cared for may have had very high numbers of admissions as was the case in the consumer survey where up to 30 admissions were reported during that time by one respondent.

Carers reported that the cared for person's longest stay in hospital for mental health issues ranged from three or more weeks (52.5% - n=21), two weeks (12.5% - n=5), to 27.5% (n=13) reporting admissions of one week or less. These findings are very similar to consumers' reported rates with one distinct difference: three day admissions were reported by 22.5% (n=9) of carers. This may be in line with a pattern of the Mental Health Act and three day detention orders with discharge for a substantial proportion of consumers with BPD, and carers being more aware of this than consumers (only two of 53 consumers reported three day admissions). As with the consumer BPD survey, what these findings suggest is that the hospital treatment for BPD is highly variable and that treatment for BPD and comorbid diagnoses is also variable for this population.

Of the 40 carer respondents who answered questions about whether the person cared for had involuntary hospital admissions, almost three quarters (72.5% - n=29) said 'yes' which was similar to consumers' responses (66% - n=35)(p=0.50). A further 22.5% of carers (n=9) said 'no' and 5% (n=2) of carers said they 'didn't know'.

Carers' responses to further questions about public hospital admissions raised some significant concerns. The first of these was that almost half of carers (48.6% - n=18) reported that they had never been involved with the decision making of these admissions. This may be related to carer preference, although the responses of nine carers, who took the time to make further comments, suggests that they had wanted to be involved but were often refused by service providers. The survey did not allow respondents to choose more than one option. Therefore, it is unclear how involved carers were in the other treatment decisions and processes during the admission. This does not, however, discount the large percent of carers who reported never being involved (Figure 8).

**Figure Eight: Involvement of Carers in the Consumer's Hospital Admission (n=40)**



The second concern was that 57.5% (n=23) from a total of 40 carers reported that they had experienced times when they had asked for the person they cared for to be admitted to hospital but had been refused. This figure was almost identical to that of consumers with BPD. Almost one third (31.3% - n=5 from a small total of 16) said that a psychiatrist refused the admission and 18.8% (n=3) did not know who refused their admission to hospital. By comparison, almost twice the percentage of consumer respondents (32%) did not know who refused. However, sample sizes are too small to show whether this difference was significant and the data is not matched in terms of carer-consumer dyads. Potential differences in consumers' and carers' levels of communication with hospital staff could be explored in further research. Eight carer respondents took the time to make further comments, with seven out of the eight reporting that the refusal had been made by the emergency department psychiatrist or the community emergency team, and one reporting the refusal came from a drug and alcohol services doctor.

Sixteen carers took the time to provide more detailed information about the issues surrounding the refusal of the person to hospital. All of these responses portrayed highly distressing situations for both the carer and the person, often involving serious suicide attempts. Some were very long responses, recounting multiple crises and refusals of pleas for help by the carer, and many demonstrated highly fragmented care systems and confusion about communication and who was responsible for serving the needs of the person with BPD during the crisis. As with persons with BPD own experiences, carers experienced inconsistency and discrimination in the process of seeking help for the person cared for, as the following examples show:

*'I rang many times for help during a psychotic event but was just told to ring the police.'*

*'Although I received sympathy I was told that people with BPD are very difficult to treat and that evidence suggests that hospitalisation reinforces self-harming behaviour and that people with BPD are better off in the community (I have had such a conversation with a Director of Emergency). I suggested that I was concerned for his safety and felt that he may commit suicide or seriously injure himself (at the time he had hundreds of deep cuts across his arms and legs requiring numerous stitches). During the most challenging time, he had serious issues relating to both substance abuse and self-harm (and suicide threats) and I felt that the medical system wanted to push him towards a drug and alcohol service (and vice versa). There was absolutely no recognition of the interaction of these problems or the need for a coordinated response.'*

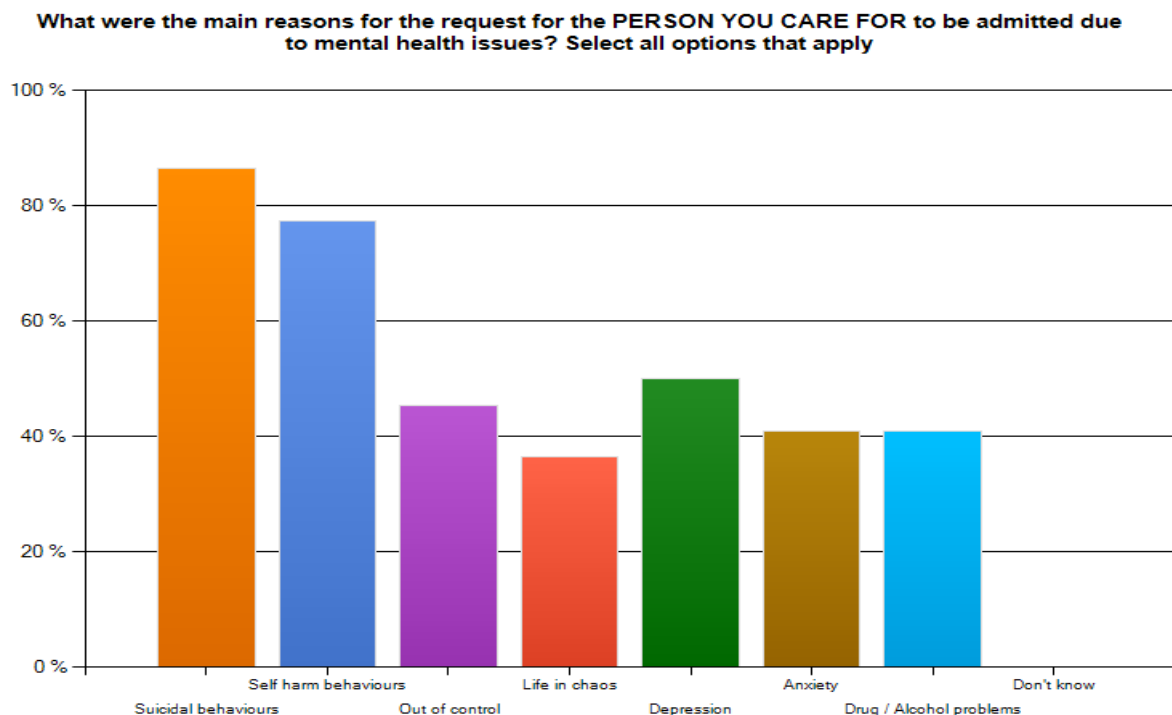
*'I was not involved or listened to when I requested for the E cat team to call me to discuss my daughter's behaviour which resulted in her arriving at the emergency dept of this hospital (she had attempted suicide). When the E cat team decided she was well enough to go home some nine hours after she had arrived at the hospital with the police they called to tell me she had just been discharged and had in fact left the building.'*

Of the 22 carer respondents who answered further questions about their experience of seeking hospital admission for the person they cared for, the main reasons for this request were directly as a result of suicidal behaviours of the person (86.4% - n=19) and self-harm behaviours ((77.3% - n=17) (Figure 9). Consumers with BPD responding to this question were asked to rate the importance of each of the question domains and all were rated as extremely important. However, because of the different structure of how



the question was asked of carers and consumers, detailed comparison is not possible, but both groups rated importance highly across all domain. The following figure provides further detail.

**Figure Nine: Carers' Reported Reasons for Requesting Admission for the Person with BPD (n=22)**



Nineteen carers gave further detail about the impact of this refusal and how it made them feel. They reported high levels of distress, anger, frustration, fear and despair and that they felt more alone and isolated because of being refused help from hospital services. The following examples demonstrate the extent of impacts on carers.

*'Where do I start? The grief, shame, guilt, sense of hopelessness and anger, Oh the anger. When someone is begging for help, and they refuse to help.'*

*'I felt hopeless, scared, and extremely anxious.'*

*'Helpless, guilty and afraid for his safety and my other children's emotional wellbeing as they were witnessing the harming behaviours on a daily basis.'*

*'I cannot find words to describe the impact this had on me especially when I got a phone call from the police an hour after my daughter had been discharged from the Emergency Dept when it was so obvious that she needed to be admitted. I completely broke down and was inconsolable as I knew this would happen if she was not admitted. I couldn't believe this was happening all over again. I barely had time to recover from the previous night's traumatic events and now it was happening all over again.'*

Carers were asked whether they had been admitted to hospital for issues related to their own mental health or the burden of caring for someone diagnosed with BPD. Of 23 respondents, 82.6% (n=19) said they

had not, four said 'yes'. On further questioning however, 15 carers reported having been admitted, but with none in the past three years. The reasons for inconsistency in responses across these two questions was unclear.

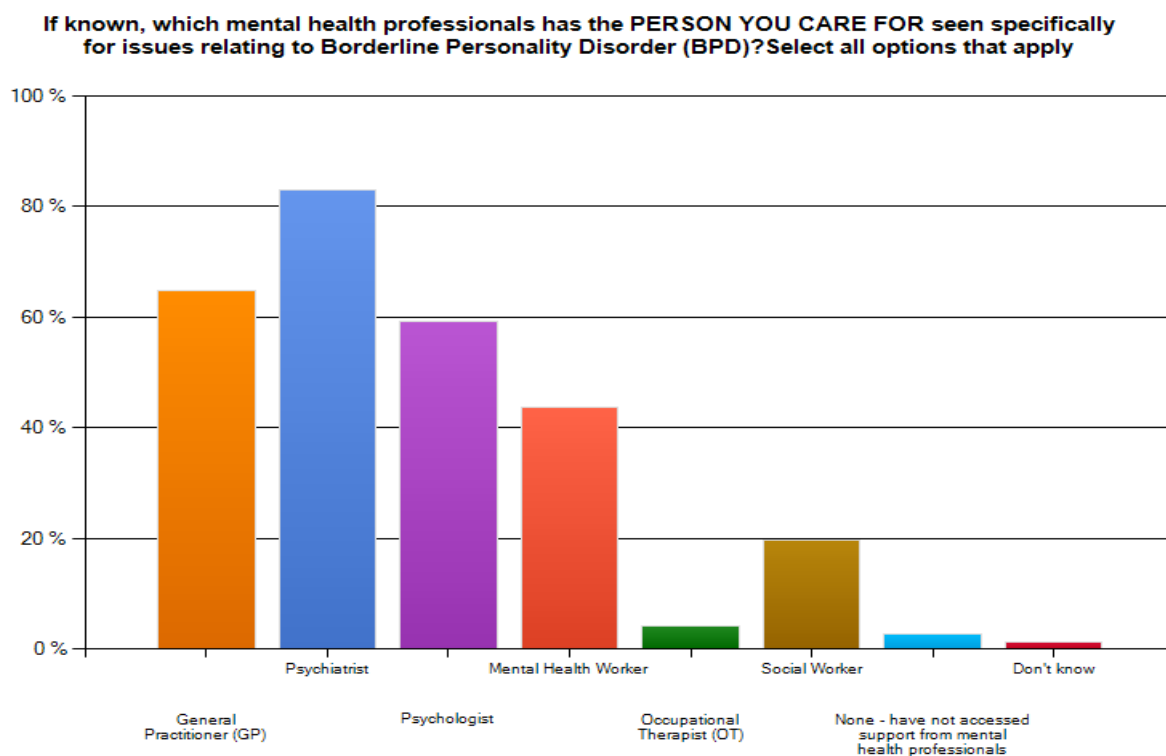
### **The Role of Private Hospitals and their Comparison to Public Hospitals (Q 57-59)**

Of the 41 carer respondents to answer questions about private hospitals, 56.1% (n=23) reported that the person cared for had been admitted to a private hospital or clinic in the past for issues related to BPD. Responses from carers about the number of admissions of the person cared for to private hospitals in the past three years compared to public hospitals over the same period were similar, with 33.3% (n=6 of a total of 18) reporting 5 or more admissions to private hospitals and 27.8% (n=5) experiencing no admissions during the past three years to public hospitals. This was in contrast to consumers with BPD who reported more admissions to public hospitals. The longest stay in private hospital for the person cared for was reported by 61.1% (n=11 of 18 responses) of carers as three or more weeks, with very low responses across the other shorter admission lengths. Further questions exploring issues surrounding private hospital admissions were not asked of carers, therefore further comparisons between public and private hospital care cannot be made.

### **Caring for a Person with BPD and the Role of Mental Health Professional Care**

Carer respondents reported that the person they cared for saw a range of mental health professionals for issues related to their BPD, with most of the 71 respondents to this question reporting psychiatrists as the main professional group (83.1% - n=59) and occupational therapists as the least seen professional group (4.2% - n=3). A small number (2.8% - n=2) reported no mental health professionals involvement (figure 10).

**Figure Ten: Carers' Report of Mental Health Professionals Seen for Support of BPD (n=71)**



Of those who reported that the person with BPD did access mental health professional support, 45.3% (n=29 from a total sample of 64) stated that they had done so for more than 10 years. Much smaller percentages were reported for all shorter time frames.

### **Support for being a carer**

Responses to questions about the extent to which mental health professionals had supported carers for issues related to caring for a person diagnosed with BPD (n=63) were varied across the spectrum of 'very supportive' to 'not supportive' with most professional groups not especially more prominent. The only differences were the ratings for GPs, with 40% (n=40) of carers rating them as 'supportive' and 15.0% rating them as very supportive. The status of 'not applicable' was rated prominently across all health professionals except GPs (Table 15). It would seem that GPs are an important source of support for carers. Twenty-three carers took the time to make further comments and the importance of consistency of support over the long haul was emphasised by many respondents.

**Table Fifteen: Carers' Perceptions of Support from Health Professionals for Them as Carers (n=15-60)**

	Very supportive	Supportive	Neutral	Not Supportive	N/A not used	Response Count
Select all options that apply	6.7% (1)	0.0% (0)	6.7% (1)	20.0% (3)	<b>66.7% (10)</b>	15
General Practitioner (GP)	15.0% (9)	<b>40.0% (24)</b>	10.0% (6)	15.0% (9)	20.0% (12)	60
Psychiatrist	12.1% (7)	13.8% (8)	17.2% (10)	22.4% (13)	<b>34.5% (20)</b>	58
Psychologist	24.1% (13)	14.8% (8)	11.1% (6)	16.7% (9)	<b>33.3% (18)</b>	54
Mental Health Worker	10.5% (6)	22.8% (13)	15.8% (9)	14.0% (8)	<b>36.8% (21)</b>	57
Occupational Therapist (OT)	9.1% (4)	2.3% (1)	4.5% (2)	2.3% (1)	<b>81.8% (36)</b>	44
Social Worker	10.2% (5)	4.1% (2)	8.2% (4)	10.2% (5)	<b>67.3% (33)</b>	49
None / not accessed support as a carer	3.8% (1)	0.0% (0)	0.0% (0)	7.7% (2)	<b>88.5% (23)</b>	26
Other (please specify) #	9.5% (2)	4.8% (1)	4.8% (1)	0.0% (0)	<b>81.0% (17)</b>	21

# - survey did not allow 'other' to be named

### Support and Education Provided to Carers

Mirroring the results of earlier questions that showed significant gaps in carers' involvement in admission of the person to hospital, carers' responses to questions about whether mental health professionals had helped them to understand how to help manage the person's early warning signs and risk of suicide or self-harm also showed large gaps. For example, 55.4% (n=36 of 65 respondents) reported that mental health professionals had not helped them to understand these issues. In addition, a majority 73.4% (n=47 of 64 respondents) had not received a crisis plan from mental health service providers for the person they care for.

### The Issue of Self-Harm and Suicidal Behaviour from the Carers' Perspective

Sixty-four of 73 carers nominated to complete this section. However, response rates across the questions in this section were very low, and were zero for a number of questions.

- No carers responded to the question asking whether the person they care for had ever displayed risky behaviours.
- No carers responded to the question asking whether the person they care for had ever self-harmed.

It is likely that responses to this question and other questions were self-evident given the many previous quantitative and qualitative responses. These questions may also have been too distressing for carers to

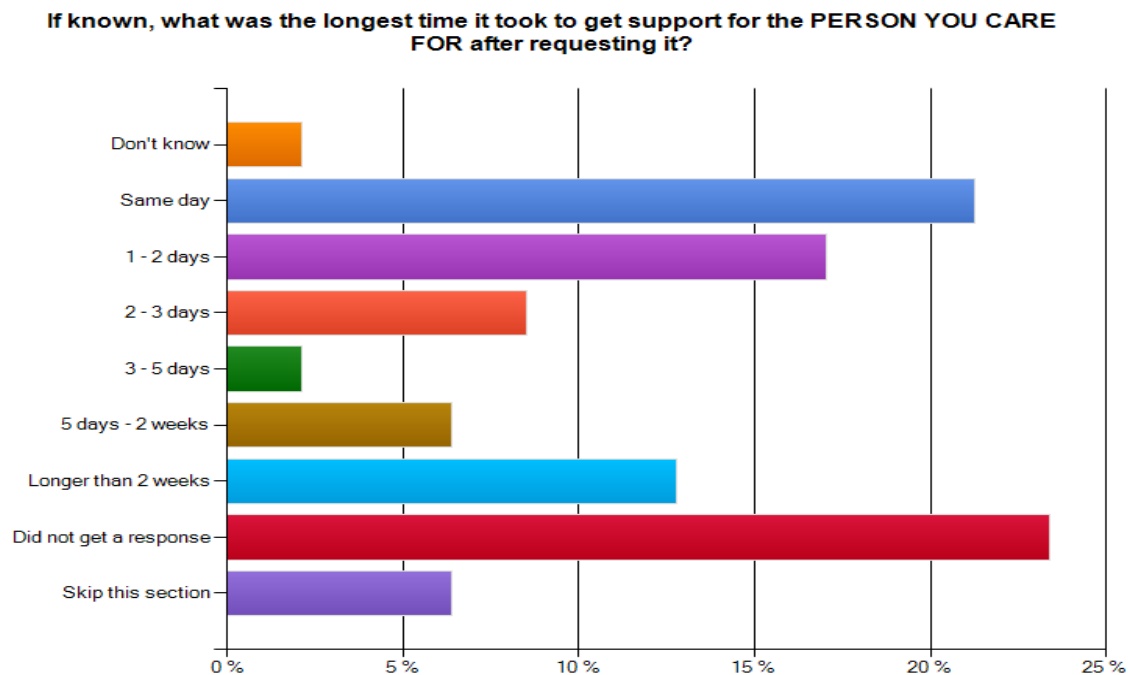
complete, although this is unclear, given that 60 carers responded to the question asking if the person they care for had ever attempted to end their life. Seventy-five percent of respondents said 'yes' (n=45), 15% said 'no' (n=9) and 8.3% (n=5) said they didn't know. This result is in contrast to the 100% of consumers (n=91) who said that they had attempted to end their life. This result suggests that some carers may not be fully aware of suicide attempts by the consumers they care for and this is supported by consumers' self-report of non-disclosure.

## **Carers' Report of Responsiveness of Services to Crisis, Self-Harm and Suicidal Behaviour**

From a respondent sample of 63, carers' report of the length of time that mental health professionals take to respond to the person cared for showed a mixed spread of responses from the same day (25.4% - n=16) to 15.9% (n=10) who stated that mental health professionals do not respond. Upon collapsing results, 33.3% (n=21) reported a response from mental health professionals within two days and 66.7% (n=42) reported a response of longer than this, including not at all. This becomes concerning when we also acknowledge the crisis points which both carers and the BPD sufferer report as part of living with BPD.

This question was asked again at a later point in the carer survey, in the section on self-harm and suicide as distinct from the term 'crisis', as used here. Carers' responses (n=47) to that question were similar with 38.3% (n=18) reporting that the person with BPD got support the same day or within 1-2 days, and 61.7% (n=29) reporting a response of longer than this, including not at all. However a higher proportion of carers than consumers (6.5%, n=6) that responded to this second version of the question which asked what the longest time was that it took to get support for the person cared for after requesting it (23.4% - n=11) reported that they did not get a response (p=0.004) (Figure 11). This perhaps suggests that services are making different judgements about need and crisis when assessing the carer versus the consumer with BPD.

**Figure Eleven: Carers' Perceptions of Response from Services for Consumer's Needs (n=47)**



Further questions about responsiveness of services when the person cared for is in crisis elicited a range of patterns across the various mental health service professional groups. None were rated as 'very responsive' by carers. GPs (63.8%) were more commonly rated as 'very responsive' or 'responsive' by carers (n=37 of 58) compared to other professionals, and psychiatrist were further noted as 'not responsive' (30.2%) (n=16 of 53) by a greater number of carers than any other profession (Table 16).

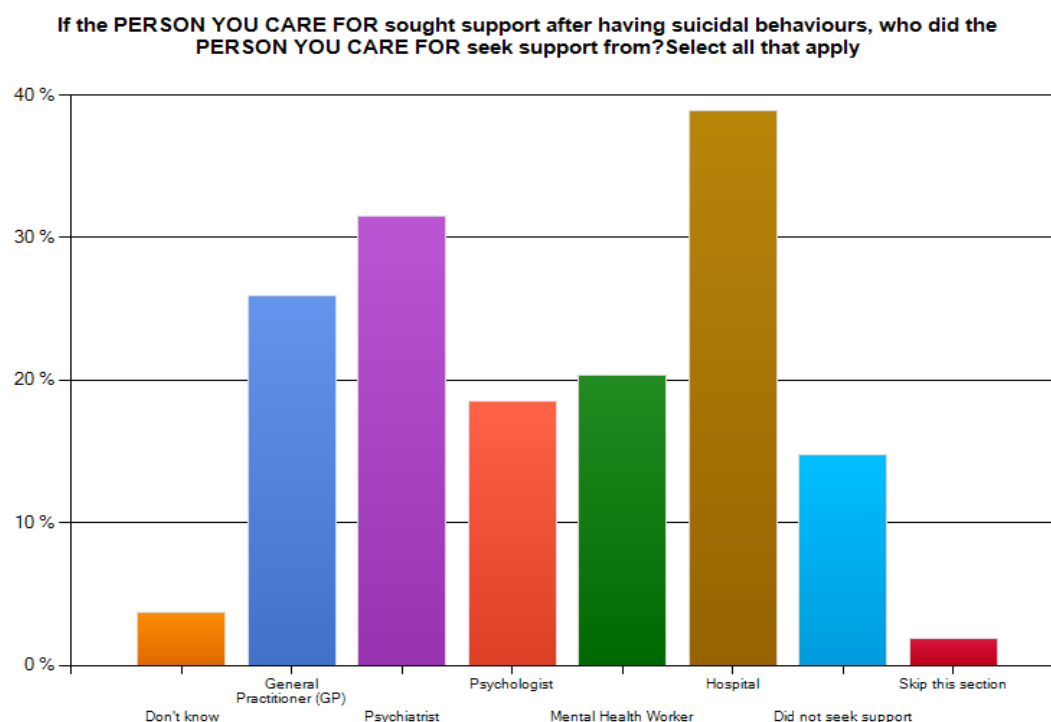
**Table Sixteen: Carers' Ratings of Services' Responsive to their Request Requests for Help for the Person (n=21-58)**

	Very responsive	Responsive	Not responsive	N/A not used	Response Count
<b>General Practitioner (GP)</b>	<b>22.4% (13)</b>	<b>41.4% (24)</b>	20.7% (12)	15.5% (9)	58
<b>Psychiatrist</b>	11.3% (6)	<b>30.2% (16)</b>	<b>30.2% (16)</b>	28.3% (15)	53
<b>Psychologist</b>	<b>19.1% (9)</b>	<b>29.8% (14)</b>	19.1% (9)	<b>31.9% (15)</b>	47
<b>Mental Health Worker</b>	15.4% (8)	25.0% (13)	21.2% (11)	<b>38.5% (20)</b>	52
<b>Occupational Therapist (OT)</b>	4.4% (2)	2.2% (1)	6.7% (3)	<b>86.7% (39)</b>	45
<b>Social Worker</b>	8.5% (4)	4.3% (2)	10.6% (5)	<b>76.6% (36)</b>	47
<b>None - have not accessed support as a carer</b>	0.0% (0)	0.0% (0)	3.4% (1)	<b>96.6% (28)</b>	29
<b>Other (please specify) #</b>	0.0% (0)	4.8% (1)	0.0% (0)	<b>95.2% (20)</b>	21

# - survey did not allow 'other' to be named

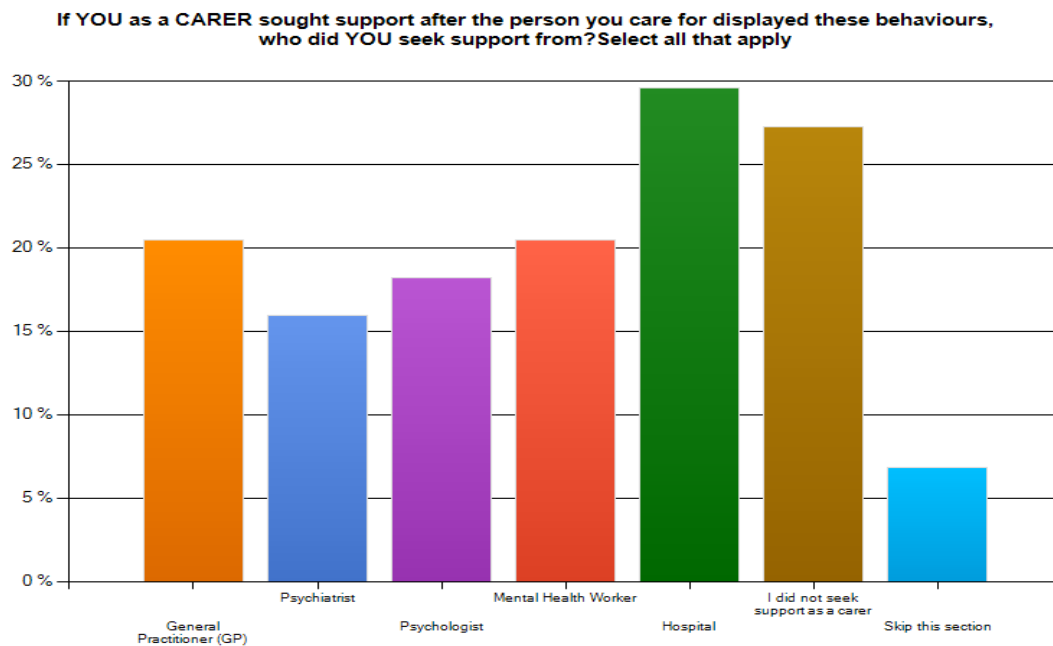
After self-harming by the person with BPD, 38.9% of carer respondents (n=21 of 54 respondents) said that the person they cared for had sought help from hospital emergency departments. This is similar to the consumers' report of GPs being the health professional group with whom they most often seek support from in these circumstances (48.3%, n=42 from 87). However, the question was inconsistently applied across the two surveys, as consumers were not given an option to nominate hospital from the list of options. In addition to this, carers were responding to suicidal behaviour and consumers were responding to self-harm. The range of professional services that carers reported the person sought help from is shown in figure 12.

**Figure Twelve: Support Sought After Self-Harming – Carers' Report (n=54)**



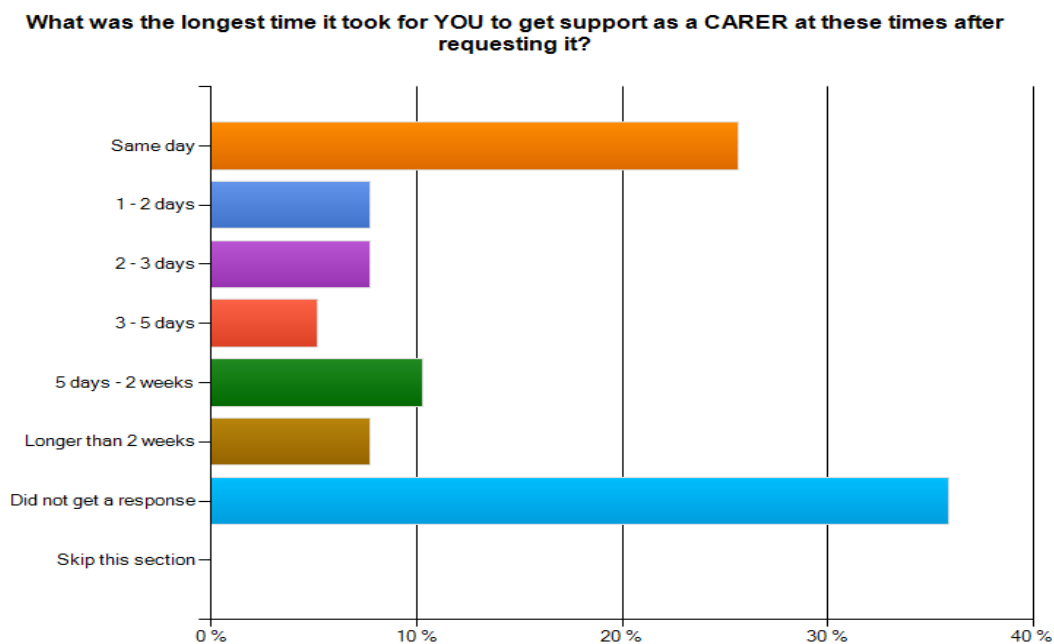
These results contrasted with carers' report (n=44) of the health professionals that they as carers sought help from when the person they cared for displayed these behaviours. Carers were slightly less likely to seek help from psychiatrists (15.9% - n=7) and more likely to seek help from staff at the hospital emergency department (29.5%, n=13). This may reflect the limited communication that many carers have with the psychiatrist who sees the person they care for. It may also reflect hospital emergency departments as being the only perceived option for many carers. Of concern, 27.3% of carers (n=12) did not seek any help for themselves. The range of carers' help-seeking behaviours is shown in Figure 13.

**Figure Thirteen: Who Carers Said They Sought Help from When the Person They Cared For was Suicidal or Self-Harming (n=44)**



Similar to the consumers who they care for, more than a third of carers 35.9% (n=14 from 39 respondents) reported that they did not get a response to their requests for help during this time from health professionals within each service. If these figures are collapsed 33.3% (n=13) of carers got support within 2 days but 66.7% (n=26) had to wait 2 days or more and more than half of these did not get any response. The range of responses is shown in figure 14.

**Figure Fourteen: The Response Time Taken by Services when Carers Requested Support when Consumers were Suicidal or Self-Harming (n=39)**





The level of crisis when carers sought help was supported by their further report (n=52) of whether or not the person they cared for sought medical attention during these times. Two thirds of carers (65.4% - n=34) reported that this was the case and further, that this overwhelmingly involved hospital emergency department contact (86.7% - n=26 of 30 respondents), with the remainder attending a GP.

When asked further questions about the experience of emergency department treatment for the consumer's self-inflicted injuries, no carers stated that this occurred immediately. One of the small sample of 4 carers reported that this took more than eight hours.

In 76.5% of cases (n=26), carers reported that the person they cared for was referred to a mental health professional as a result of the self-harming at these times. The remainder were not, and it is unclear whether the contacts were single contacts or whether ongoing support in the community was provided.

## **The Role of Community Support Services in Supporting Carers and Those They Care For**

Carer respondents (n=67) had few positive comments to make about support services. Similar to earlier responses, their response patterns suggested that they neither found them very helpful or very unhelpful. The most significant pattern across the responses was that these services were perceived by carers to be not used/not applicable for the person they cared for. Gambling support (96.8% - n=60 of 62 respondents), men's shelters (93.5% - n=58 of 62 respondents), youth shelters (84.7% - n=50 of 59 respondents) and women's shelters (82.8% - n=53 of 64 respondents). This is of concern given the needs of people with BPD and the high rates of homelessness and lack of family and friendship supports amongst this population. Table 17 provides further detail:

**Table Seventeen: Carers' Perspective of the Helpfulness of Community Supports for the Person with BPD (n=67)**

	Unhelpful	Unhelpful	Neutral	Helpful	Very helpful	N/A	Rating Average	Response Count
<b>Crisis lines</b>	9.4% (6)	14.1% (9)	9.4% (6)	17.2% (11)	6.3% (4)	<b>43.8% (28)</b>	2.94	64
<b>General groups</b>	4.6% (3)	20.0% (13)	6.2% (4)	15.4% (10)	3.1% (2)	<b>50.8% (33)</b>	2.84	65
<b>Financial</b>	7.7% (5)	15.4% (10)	9.2% (6)	20.0% (13)	1.5% (1)	<b>46.2% (30)</b>	2.86	65
<b>Housing</b>	15.2% (10)	10.6% (7)	4.5% (3)	9.1% (6)	6.1% (4)	<b>54.5% (36)</b>	2.57	66
<b>Gambling</b>	1.6% (1)	0.0% (0)	1.6% (1)	0.0% (0)	0.0% (0)	<b>96.8% (60)</b>	2.00	62
<b>Drug / Alcohol</b>	9.4% (6)	7.8% (5)	7.8% (5)	12.5% (8)	1.6% (1)	<b>60.9% (39)</b>	2.72	64
<b>Relationship counselling</b>	9.1% (6)	9.1% (6)	7.6% (5)	7.6% (5)	0.0% (0)	<b>66.7% (44)</b>	2.41	66
<b>Women's shelter</b>	3.1% (2)	3.1% (2)	1.6% (1)	6.3% (4)	3.1% (2)	<b>82.8% (53)</b>	3.18	64
<b>Men's shelter</b>	1.6% (1)	0.0% (0)	1.6% (1)	3.2% (2)	0.0% (0)	<b>93.5% (58)</b>	3.00	62
<b>Youth shelter</b>	1.7% (1)	3.4% (2)	1.7% (1)	8.5% (5)	0.0% (0)	<b>84.7% (50)</b>	3.11	59

## APPENDIX 1.

### QUALITATIVE DATA FROM CARER EXPERIENCES OF CARE SURVEY

Quantitative data is in itself reliable data, however, a critical component, especially in the survey construction, was offering carers the opportunity to expand their comments in a number of questions.

Set out hereunder is that qualitative data which enriches the content and informs the outcome of the survey.

#### SECTION ON: BACKGROUND INFORMATION

**Question 7. Do you have any further comments about this section?**

**Answered question 18**

**Skipped question 110**

- The medical profession seems to relate to me as a 'friend' without recognising me as not only a same sex relationship partner, but primary carer as well. All the information I know has come through my own research, my own networks, and my own consultation with my personal psychologist
- BPD was major diagnosis at age 13, this was later complicated through 'life' issues.
- Would have liked to be involved in the diagnosis process and be given a clear explanation and understanding about the condition. Felt ostracised. Even the diagnosis given to the patient was said with no compassion or diplomacy, just sheer arrogance from the psychiatrist.
- Many different paediatric specialists were seen when she was a child/young teenager. All were concerned about her behaviour but variable in their assessment of causes, diagnosis and treatment. Child was in-patient in hospital behaviour clinic for 2 months when quite young. Staff were not able to help her and she returned to her mother with new and excessive anxiety symptoms.
- It took us about 4 years to finally get a diagnosis for our daughter. It was not until we found a great psychiatrist in the private system, that we were given a clear diagnosis and the information and understanding of what our daughter was suffering from. Up until this time, she had had many episodes of trauma, self-harm and suicide attempts. And hospitalisations. We found that the public health system was TOTALLY incapable of helping her or us over this time
- Psychiatrist making this diagnosis refused to accept that of schizophrenia from the treating psychiatrist

- Mum was presenting symptoms for many years prior to the diagnosis; but she refused to see a professional.
- Psychiatrists generally have been very unhelpful and basically unaware or uncaring about the massive impact the patient's illness has upon the carer, relatives and others
- The diagnosis was made several years before we were told of it. It's not known who made the diagnosis but once told by the case worker in mental health, it was explained
- I bought books and read up about it myself to the best I could. There are still many aspects that I do not understand of the illness. Knowledge is power. I, as her mother and carer needed to have help in dealing with this illness and how to cope with very difficult situations. Carers/ parents have to be more a part of the treatment plan to know what's going with their loved one. Like a support group, so much more information needs to be out there for us to access. Family, friends etc. and people in general do not know about BPD and ask me what it is which I do find is very difficult to explain to them. My daughter was diagnosed at a Government run place called XXX in XXX. I only found out by chance that my daughter had BPD when in a crisis at a hospital. How's that for bad communication. I had no idea what I was dealing with for many years. Thank you for this opportunity.
- I researched and obtained literature from libraries including university libraries in order to learn about BPD. XXX was also prescribed by a psychiatrist for a period of approx. 12 months - of course the result was addiction, continual increase in dosage and dreadful side-effects and withdrawal. Now only taking anti-depressant. NB: this medication should only be prescribed for 10 days or less.
- Yes it has been only in the last 12 months that we were told of this diagnosis. Was under the impression that it was depression
- None
- My son did not accept the diagnosis and does not talk about it
- The diagnosis is informal. A trusted GP he saw is a relative and has strongly suggested (without breaking confidence) that this is the case
- Recent diagnosis for BPD. Previously treated for ASD, anxiety and depression.
- No
- I have never heard of BPD before in all my years of interest in medical diagnosis. Where did this problem originate from? Do Psychiatrists have to pass studies in this area? Consulting Psychiatrists

that I know do not list BPD as an interest .When you say "Borderline" what borderline are you inferring? In other words, who came by this disorder and is it a legitimate medical term?

- My daughter has suffered with anxiety disorders and then personality disorders due to domestic violence however no services available at the time when she was 14 to support me when I escaped a violent home situation - in 1999 - as I am aware of the symptoms I believe my daughter suffers with a personality disorder her father suffered from anti-social disorder - in 2000 my daughter was made to see a child psychiatrist at 14 years and only visited twice - also some attempts at the time to seek services with XXX (NGO) and did not continue - now suffers with depression and has two small children in a de-facto relationship which is dysfunctional - I feel there is no services she can access because she does not have a diagnosis - so I have struggled as parent - trying tough love strategies etc. and her siblings suffer with her angry outbursts and does not take responsibility for her actions and uses the grandchildren as emotional black mail - I could go on.....
- NIL
- I work in a residential setting that delivers treatment to both male and female clients over 18 years of age with a primary diagnosis of BPD. I chose one current client to base my answers on
- Although it was not explained I have a sound understanding as a mental health worker
- It was only by reading that I learned what BPD was
- After accessing public health (XXX (public) Adolescent) I went to a private person who diagnosed depression and anxiety; after a while I managed to change GPs and with the help of my workplace (XXX) I organised a session at XXX (NGO) where the diagnosis was my daughter met the criteria for bipolar; however, the self-harm and inability to deal with her emotions correctly made me suspect she also has BPD.
- Not relevant
- Working in mental health I have an understanding of BPD myself and the diagnosis was discussed between myself and the counsellor and G.P. This was discussed by them to my son also.
- My son's father, my ex-husband, also suffers from BPD, therefore the diagnosis was a lot easier to reach for my son
- No
- Very little support was placed around the family at the time - it seemed very little support was available generally for the family/carer OR the consumer.

- Nil
- There is no discussion between myself and the psychologist. She seems to be interested only in prescribing drugs.

## **SECTION ON: IMPACT OF MENTAL HEALTH SUPPORT SERVICES ON YOU AS A CARER**

**Question 5.**     *Do you have any further comments about this section?*

<b>Answered question</b>	<b>24</b>
<b>Skipped question</b>	<b>104</b>

- More funding, more resources, more understanding is needed not only for treatment and support/care for BDP patients but carers as well. We are the people who catch our loved ones at their most vulnerable, and once they are more stable, it can take months/years to heal and recover.
- The hospital staff in general when my sibling was in a locked ward or open ward were often not helpful and indeed in the locked ward, would purposefully keep me waiting before they would unlock the doors to let me leave, even though I had made my intentions known and they had seen me within their glassed areas
- DBT is over rated as an intervention and denies a sense of self to sufferers
- Knowing where to get this support. Finding a professional that understands and is sympathetic and constructive in their approach to my problems (as a carer). Ongoing support, as the problem does not go away, only fluctuates from one crisis to another with occasional 'lulls' (to put you off guard???) What do I do as a grandparent, when I see similar symptoms surfacing in her child???
- Would like to see some networks or support groups established so as to obtain valuable support as a carer.
- There was often the feeling that the mother was exaggerating information about the child's extreme behaviour. Or that it must be due to bad parenting. Yet there was no neglect, abuse, violence or addictions in the family. There was lots of cuddling, reading stories every bedtime, highly nutritious meals, friends over to play, activities and toys. Mother read many books on child behaviour and used many strategies suggested, with limited and short-term results. Older child in family had no signs of BPD. Specialists were often sympathetic but seemed to be clueless about what to actually do about the problems. A common feeling was that this family was "put into the too-hard basket". Initial diagnosis when a toddler was that she had suffered from minimal brain damage when born. After years of chronic trauma and stress, mother developed uncontrollable diabetes, which she is now dying from (as her own psychiatrist warned would happen if the situation did not improve).

- I did not seek support from services once I had the bad experience of unhelpful support from the hospitals and PDRS sector
- The public health system was totally inadequate in giving us the help or care that we needed and the intensive care that our daughter needed. It was in fact very obstructive in guiding us toward effective help. We were told that our daughter would not be able to access help other than what she was getting in the public health system because of some of the aspects of her illness.
- See no. 3
- Support and services are very limited in country areas
- The time and anxiety around trying to gain access to support for myself has been extremely taxing in its own right. Time spent researching and trying to make sense of the different services and what, if anything, they can do to help. It never ends. Finding accommodation, keeping things stable so that the accommodation is maintained. Trying to work part-time and keep my sense of self whilst caring for my daughter is such a strain. I love my role as XXX (*assistant in NGO sector*) in aged care and so desperately want to keep it up but, right now I am contemplating AGAIN whether or not I should leave and do more for my daughter to try to ensure that she has a reasonable future when I am not here. To try to encourage, boost her confidence, allay the fears, dampen the anxiety, dry the tears, help her to move about in society etc. etc. etc.
- For 18 years the person being supported either refused to seek professional help, or would not return to the few professionals that were seen. None of the early professionals diagnosed BPD. One psychiatrist diagnosed "high sensitivity". With no diagnosis, or incorrect diagnosis, for 18 years, Mental Health Services were non-existent.
- Again this has to do with govt dept namely XXX Disability Services. I am frequently trying to explain to them the need for additional funding for me to look after my son at home. As he has a neurodegenerative regressive fatal illness called Batten Disease, I have explained that I will not be relinquishing my care of him even though they have suggested it from time to time. They don't seem to realize it would cost the govt more money if I wasn't prepared to look after him at home. Knowing what I know though I would never let him out of my sight in order to be cared for in a residential half way home or nursing home.
- My son has never sought help. I don't know what to do.
- Isolation is a huge factor which disenfranchises carers and reduces confidence. BPD sufferers are highly intelligent and their behaviour leaves you exhausted and disillusioned, unable to go out in to the world beyond what is necessary to keep a family and home together.
- Challenging behaviours - out of hour's emergencies - no supports. Private specialists can't be accessed out of hours. When emergencies occur, self-harming, suicide threats ~ this places huge amount of stress and strain on families to drop everything (usually work that can cause financial and work pressures). No support to assist family with everyday needs while carers are picking up the pieces (attending to other family commitments - siblings to school etc.). Respite?

- No
- I feel there is not enough support out there for those who fall into the gaps and in the interim another generation comes along - I feel that more should be done for the children of these parents when they present to GPs due to children having eating problems - mental health is still behind in a lot of areas and not recognised and not everyone presents as the typical BPD under privilege - it should not be thought of as those who are from disadvantaged families - no education or from at least one loving parent - domestic violence is across the board - she is a very intelligent young female who fell through the gap and I was to raise 4 teenage children and she was the third in line - and now we have two young children raised by someone who cannot raise herself
- As above and now I have learned where to find this support - carer support groups have been a great help.
- Without private health insurance which they cannot afford none of the family receive adequate support. My husband and I provide free accommodation in a unit we own but this is all we are prepared to commit
- After my daughter slashed her wrists, she then hid the damage till the next day. I took her to the GP to have stitches: The GP said, "I've seen worse". That hurt. My daughter said she saw it as a challenge to do away with herself. It was awful.
- It comes down to getting my son to identify himself that he needs to access help. If he got help I would be fine.
- Carer supports via Carer Support group & counselling were available and helpful, but there is still no carer support specific to BPD in XXX(state).

## **SECTION ON: IMPACT OF MENTAL HEALTH SUPPORT SERVICES FOR THE PERSON YOU ARE CARING FOR**

**Question 5.** *If known, from the above services, what has been the least helpful/prevented/interfered the most with the recovery of the PERSON YOU CARE FOR? For example, unable to access support when they needed to, not taken seriously, affordability or availability of support services, etc.*

<b>Answered question</b>	<b>56</b>
<b>Skilled question</b>	<b>72</b>

- I stopped relying on the expected support and did my own research to help myself.
- Medications and the lack of information and advocacy around alternatives to the normal. Several prescribed anti psychotics have triggered extensive and drastic suicidal ideations, and despite the acknowledged link between medication and suicide attempts, the medical professionals have not taken the need to find alternatives seriously. Furthermore, the lack of accountability and follow



ups from the majority of medical professionals has seen us both become disenfranchised, disappointed, disengaged, and clinging on to the bare bones of hope, that somewhere, sometime, someone will be able to provide the support we both need.

- The absence of consistent support when the psychiatrist/psychologist has been away on leave. Turnover of staff at hospitals. Temporary staff adapting or changing medication without the knowledge of regular psychiatrist. Abusive behaviour by nursing staff which has made my sibling fearful of being in certain wards in hospital. Following are my own observations and information given to me when my sibling has been in a locked ward: Lack of respect shown to my sibling and other patients, especially within the locked ward. My sibling not being taken seriously when complaining of simple things like a headache or being unable to eat a certain food type. Refusal to be able to sleep, being made to stay up all day, even though incredibly tired, often due to medications which have been prescribed. Bruises on her arms and legs consistent with being manhandled by more than 4 staff.
- As stated discrimination against the patient and an arrogant alliance to DBT as a model that will do it for all.
- Professionals changing - going to a different job/town/holidays etc. - "not there when you need them". Not taken seriously. No money.
- Hospital possible admission she was too frightened by the hospital situation and wouldn't stay needed to be admitted on a weekend and was put in room on her own with a security person for hours
- Not taken seriously and also the stigma attached to mental illness.
- I think it would be helpful for the mental health support to follow up with him to keep him on the right track and motivated to continue therapy
- When my niece was about 6 years old, she was put into XXX(*public*)residential clinic for 2 months. The staff believed they would find that her behaviour was not nearly as bad as my sister claimed and that their behaviour intervention strategies would greatly improve my niece's life. Neither of these things happened. But there was no explanation for why there was no improvement or what my sister could do at home to help matters. On top of that, my niece came away with severe separation anxiety and could not bear to leave her mother to go to school. She was excessively clingy for years.
- N/A
- N/A
- The illness itself!
- In the public system-- Lack of effective action, an attitude of contempt, frustration and negativity shown towards us. Not being given a clear diagnosis of her illness. We felt that very few of the

health care workers (From the top down) wanted to take responsibility for the decisions they made in relation to our daughter's illness. Lack of consultation with us in relation to treatment

- Hostility and aggression from those apparently supposed to offer help
- Not taken seriously lack of understanding by medical profession
- Mental health team from public hospitals.
- Affordability is a problem, as she is on a Disability Pension only, e.g., could not access private hospital treatment or a private psychiatrist.
- Not recovered. Unable or wanted to seek services due to past bad experience at XXX(*public*), .as mentioned earlier no admissions into hospital, but has been to emergency department for 2 serious self-harm cuts on her arms.
- XXX and XXX prescribed by psychiatrist has been most unhelpful and detrimental. Also counselling from psychiatrist not anywhere near the order of the excellent counselling by psychologist.
- Poor psychiatric diagnosis.
- Disability Services XXX and some service providers my son uses for community respite
- Mental Health Services & the Mental Health Act
- No services available. Admitted to MH when Psychotic incident and then discharged for family to deal with.
- Feeling like that they are not taken seriously
- He has been refused support from psychiatrists who do not 'believe in' BPD or do not wish to treat patients with it. In crisis situations (i.e. serious self-harm) he has been offered very short-term hospital stays (with no follow up support) as 'evidence suggests that people with BPD who are self-harming are better off in the community'.
- Not taken seriously
- Attitudes of mental health staff department of child services not doing their job and teachers not asking hard questions when there is clear neglect happening
- Not diagnosed early enough. Lack of courage on part of practitioners to say what is happening and help the person accept it.
- Stigma, turnover of case managers has been too high and disruptive when trust is a major issue.

- Developing a crises plan. Parents are left to fend to their own resources during emergencies situations with lack of knowledge, skills and understanding. - sometimes, unintentionally making a volatile situation worst and affecting recovering.
- Lack of knowledge by the regular psychotherapist conducting CBT. No past information was a lead up to not being able to give correct diagnosis. Not taken seriously, unable to access correct support when needed.
- Families' lack of knowledge/education
- Public hospitals ED - often patients are treated badly and not taken seriously
- Lack of hospital beds
- Unable to access - need diagnosis first - affordability as she does not work - availability of support services and location cannot drive
- Unable to access support when they needed to, not taken seriously, and when crucially needed support services were not available because he had been banned from the service.
- Not taken seriously
- Reliance by health professionals on family to provide care
- She has never been taken seriously - has had hospitalisation but never ever follow up. Housing has been difficult and the cost of private counselling services are out of my budget and definitely out of hers. She is unable to gain employment because of the evidence of self-harm.
- na
- Stupid statements like "I've seen worse" from GP. Lazy diagnosis from very expensive private adolescent psych who had her own smarmy opinion
- N/A
- Being badly treated, considered a troublemaker
- Not taken seriously.
- Mental health team didn't come when needed, wasn't admitted into hospital even though she was psychotic and was sent back home for us to deal with
- State MH teams - non responsive, didn't take feelings/thoughts seriously. Elevated stress levels
- Too much medication- too many benzos

- Not taken seriously.
- Support worker
- Not taken seriously CBT
- Not taken seriously when taken by ambulance to A & E, after 'collapsing in foetal position' in Psychologist's office during counselling session. Crawled under chairs in the 'waiting room' at A & E during extensive waiting period, and was simply told by a nurse 'get out of there'. No triage undertaken. (I was interstate at the time, so only learned of this on returning two days after the event.)
- Accessing quality and understanding MH crisis clinicians has been an issue at times. It seems some clinicians believe BPD stands for Bad Personal Discipline and doesn't warrant the level of care of other MI's
- Being sent from pillar to post and not receiving any ongoing care.
- Isolation. Support and community groups not allowing her to join, when she has done nothing disruptive. She's heard every excuse from 'there's too much paperwork involved' to 'we don't think you'll be happy here because we tend to be more active and hold dances etc.' Mum loves dances!
- Not taken seriously by the mental health clinicians: In fact being told that she was behaving badly.
- The most frustrating occurrence is the cancellation of respite at the last minute and nobody available to replace the support worker
- His Psychiatrist

## **SECTION ON: GENERAL PRACTITIONERS**

**Question 7. Do you have any further comments about this section?**

**Answered question 18**

**Skipped question 110**

- GP's need training to support patients. They too can suffer boundary transgressions
- I needed this GP 15 years ago.
- Psychiatrist was most obnoxious and condescending and most unhelpful.
- My sister was unaware that some of these specialists might help, so she did not know to ask for them. Most of her professional help was through emergency hospital visits, or others services

arranged by psychiatrists/paediatricians or NGOs she contacted herself. E.g. Yes Housing through XXX(NGO), referrals from XXX (*National NGO*)

- Our GP has consistently supported our entire family in relation to our daughter's health and the impact it has had on the whole family. We feel that he could have had better access to more informative resources both locally and systemically
- My daughter received help when she was a teen but not much compassion or understanding or guidance since getting older
- My daughter basically handles her own health care now and lives independently in the country. She is caring, but very strong willed and it is better this way. She is also middle aged and independence is the best thing for both of us. I think, over time, she has found what works best for her, where she can have the most freedom and control and I really admire her for this. I also think the combination of a good psychologist, whom she was able to access under the recent Medicare rebate system and XXX (*church*), plus doing Cognitive Behaviour Therapy Course a few years ago, has really helped her to mature and grow. It has been a long hard road - 35 years!
- I am the main disability advocate for my son. I request GPs to organise referrals/ visits to specialists if required otherwise I contact professionals myself and organise what is required.
- My own GP has not referred my daughter but her own GP has.
- GPs have been the most judgemental professionals that we have encountered. It has not been helpful or positive to share information and to garner support from GP's
- Initial GP did not respond to the early signs of BPD in my sister. Referred for treatment for anorexia nervosa/ bulimia, however symptoms of BPD started to become more prevalent and therefore lead into suicide attempts, and then resulted in a Hospital Admission, and it was then that my sister was diagnosed by a Psychiatrist with BPD/ as well as Eating disorders.
- As a psychologist in an acute mental ward of a private hospital I have very few dealings with the GP
- They need to build a rapport and trust - this is not as easy said than done as I know how hard it is not to be misunderstood - takes time
- I think the GP has tried to help but again - it's the too hard basket.
- The G.P has supported me but I feel I am a burden to him.
- While my daughter was in the private health system, her GP usually referred her to a psychiatrist when required, but since she transferred to the public system [about 5 years ago] referrals have been made whenever needed within her mental health team or by her Key Worker. This has been very effective, but depends largely on having a good, motivated and compassionate Key Worker.

- GP has provided no counselling or support - diagnosed me with depression instead of listening to the situation - which was refuted, but got a referral to a psychologist which was productive in the end. Didn't take the impact being a carer of someone with BPD could be, wanted to prescribe antidepressants - all in a 5 min consult!
- We have individual GPs so level of care has differed. My experience as carer has been positive with my GP. The person I care for's experience has been a lot less positive. Mainly interference with diagnosis and care options and in some instances medication. This has meant instances of health issues going undiagnosed or put down to stress or Psychosomatics. In one instance a brain tumour went undiagnosed for significant length of time as was put down to stress headaches. An NGO support worker got support through local A&E unit which lead to discovery and treatment.

### **SECTION ON: HOSPITAL ADMISSIONS – PUBLIC**

**Question 3.** *If known, please provide further comments/information relating to this refusal of hospital admission*

<b>Answered question</b>	<b>16</b>
<b>Skipped question</b>	<b>112</b>

- After the most recent spate of suicide attempts, I was begging for longer term help, stability and safety for her. Hospital system just saw that she was admitted with someone and therefore wanted to assume someone was at home. It was only when I insisted that as a non-trained professional, I did not have the skills, ability, strength to continue, let alone the fact we are no longer living together, meant they had a duty of care to look after her for more than a tick and flick, stitch you up and send you home option. She was able to stay for 2 days. Not ideal. But provided enough space for me to ensure her home was safe.
- He wanted to be admitted for a couple of weeks, was told he could stay for only 2 days
- My daughter has behaved badly in hospitals that she has been admitted to for alcohol problems and is then banned from them because the D & A doctors don't understand what BPD is and how people with BPD behave. This in turn makes it impossible for my daughter to get access to the same hospitals for psychiatric reasons. There needs to be more compassion and understanding and education on the part of D & A doctors.
- Rang many times for help during a psychotic event. Just told to ring the police
- Although I received sympathy I was told that people with BPD are very difficult to treat and that evidence suggests that hospitalisation reinforces self-harming behaviour and that people with BPD are better off in the community (I have had such a conversation with a Director of Emergency). I suggested that I was concerned for his safety and felt that he may commit suicide or seriously injure himself (at the time he had hundreds of deep cuts across his arms and legs requiring numerous stitches). During the most challenging time my brother had serious issues relating to both substance abuse and self-harm (and suicide threats) and I felt that the medical system wanted to push him towards a drug and alcohol service (and vice versa). There was absolutely no recognition of the interaction of these problems or the need for a coordinated response.

- I simply requested to the treating Psychologist that she organise admission into a hospital for my sister when I could see early warning signs. She advised that because my sister was attending counselling and "had a plan" that she could not insist on an admission.
- Upon presenting at the emergency unit - daughter was turned away because she was becoming aggressive due to lack of support from the staff. She needed help and couldn't get it. She went home and self-harmed plus took an overdose.
- My son was labelled as using the health system to hide from the criminal system. He never committed a crime. He was self-harming to the extreme and the police would take him to hospital and they would refuse to admit him.
- Following a suicide attempt by gassing in his car, my son was admitted to Prince of Wales, where he spent 10 days without mental treatment (involuntary admission). As soon as a bed became available at our local hospital, he was transferred to Manly, and discharged within one hour of arrival, still very suicidal, with no support, 2 days before Xmas. East Wing at Manly is a disgrace, their treatment for any mental patient is non-existent or inadequate
- Stated the need for community care on many occasions - community care being that of the family. Not enough beds. Didn't want to institutionalise. One memorable occasion was after XXX had been taken, unconscious, rushed to emergency, stomach pumped, and the duty psychiatrist said there were no presenting symptoms!! Sent the person home in a taxi b/c the family refused to pick the person up stating they had to be admitted to the psychiatric ward.
- My daughter recently became unwell and overdosed. She was admitted to hospital and when she was medically stable she was discharged. I expressed my concerns to the team who assessed her but they were adamant that she was fine to go home. Once home she was still in a suicidal frame of mind and continued to display signs of anxiety. The cat team were called and she was assessed over the phone. She was assessed as being suicidal. The cat team were in the process of calling the police in assisting them to have my daughter taken to hospital to be assessed when my daughter took off. The police finally located her in a bridge where she was threatening to jump off. Police mediators took about 3 hours to convince her to give up. She was taken to the Emergency Dept of a hospital. I telephoned several times during the course of the night and spoke to nursing staff. I asked that before the e cat team make a decision about my daughter could they please contact me as I would like to pass on information to them and be included in her assessment. Not only was I not included but I was not contacted by any one on the e cat team. Nine hours after my daughter arrived at the hospital after her second suicide attempt in 3 days she was discharged yet again after I had spent the night begging for her to be admitted. When I received a call telling me that she had just been discharged I couldn't believe what I was being told. I expressed my concern for the safety of my daughter and how negligent it was for the team to discharge her. I also let them know how unprofessional and ignorant they were in not returning my calls. I let them know that as a carer I had valuable information to share with them and they chose to ignore my requests to be contacted. They told me that the decision had been made and as far as they were concerned my daughter was well enough to be discharged and that she was on her way home. I told them exactly where my daughter was and that was on her way to the nearest bridge. I then called the police and they immediately swung into action and quickly located my daughter once again on the edge of a bridge threatening to jump off. She was taken back to the hospital where she was finally admitted

this time. She has been in as an involuntary patient for 24 days so far and is still being treated. If only they had listened to me as her carer when she was first admitted!!!

- After admission the CAT team called and advised that they did not see the patient exhibit signs of hostility. That the patient was lucid.
- I was not involved or listened to when I requested for the E cat team to call me to discuss my daughter's behaviour which resulted in her arriving at the Emerg Dept of this hospital. (She had attempted suicide) When the E cat team decided she was well enough to go home some 9 hours after she had arrived at the hospital with the police they called to tell me she had just been discharged and had in fact left the building.
- I was not involved or listened to when I requested for the E cat team to call me to discuss my daughters behaviour which resulted in her arriving at the Emerg Dept of this hospital. (She had attempted suicide) When the E cat team decided she was well enough to go home some 9 hours after she had arrived at the hospital with the police they called to tell me she had just been discharged and had in fact left the building.
- There have been a number of times this has taken place. Some reasons given have been lack of availability of beds, no one to transport consumer, not unwell enough (though harming self) and on one occasion worker stated " how would you feel if I admitted you and someone who really needed the bed was refused" the person I care for was at the time extremely suicidal and there was a provision in her crisis plan for short 24-48hr admissions to see off the crisis. The clinician had access to the plan but chose to ignore it despite our requests. I was left to support my person at home till Case Manager could attend next day. (This worker was counselled following our complaint & support form Case manager)
- As above
- Mum has told them she feels she can't possibly go on and they don't believe her.

**Question 4. Briefly describe how YOU as a CARER FELT and what the IMPACT was of not being able to admit the person you care for into hospital**

Answered question 19  
skipped question 109

- Where do I start?!?! The grief, shame, guilt, sense of hopelessness and anger. Oh the anger. When someone is begging for help, and they refuse to help.
- Oh no, I can't deal with him right now, it's too much!
- Devastation anger
- Devastated and alone in my wife and I misery



- Outraged at the lack of support. The most frustrating aspect was that his most serious self-harm behaviours were highly aggravated by the consumption of large amounts of prescribed benzodiazepines (albeit obviously at much higher doses than intended by prescribers). I recall several times suggesting how unbelievable it seems that outrageously poor prescribing decisions were severely impacting on his mental health but there was no support from the medical system to address these problems. I was once visited by police who had taken him to hospital due to serious self-harm the following day - they had come to find out how he was and were shocked to find out that he had not been hospitalised.
- At that point in time, my sister was withdrawn from me and I was not able to engage with her to get consent to be involved. However, when her psychologist advised that Hospital admission was not at option, I felt hopeless, scared, extremely anxious about my sister's behaviours and knew that something was very wrong and hospital was needed.
- Very angry when there are no beds available
- Devastated, frustrated, despair
- I felt powerless. I could not provide safety for the patient or for myself and others.
- Utter disbelief that any health professional (the caring industry) could be so insensitive and cruel. It's usually then left to the carer to 'pick up the pieces' and try to put a person you love, life back together.
- Helpless, guilty and afraid for his safety and my other children's emotional wellbeing as they were witnessing the harming behaviours on a daily basis. He was only 15 at this stage and when they did admit him at times he was thrown into an adult mental health unit with other unwell patients. This was having a detrimental effect on him as he was sexually abused a few years earlier by a male adult.
- I was left in charge of my son, who was still very suicidal, on my own, 2 days before Xmas, without knowing where to go for help, with most services shut for another month. I was very angry and fearful. Prior to my son's suicide attempt, I had tried for 2 months to get him some help. Because he was 21, I was told that it was up to him to ask for help. On a Thursday night, he rang the Manly crisis team to report that he was suicidal, but only spoke to a recording machine. He attempted suicide 36 hours later, and the day after he was admitted to hospital, on Saturday night, the suicide prevention team left a message on his phone, replying to his first message on the Thursday. My son attempted suicide 10 years ago, and the lack of support is as bad now as it was then.
- Frustrated, angry, disappointed, alone.
- I felt angry frustrated and helpless. I was frustrated that I wasn't being heard. I know my daughter better than anyone and I should be included in decisions that affect her treatment and or admission especially when I have such serious concerns for her safety. I cannot find words to describe the impact this had on me especially when I got a phone call from the police an hour after my daughter had been discharged from the Emergency Dept when it was so obvious that she

needed to be admitted. I completely broke down and was inconsolable as I knew this would happen if she was not admitted. I couldn't believe this was happening all over again. I barely had time to recover from the previous night's traumatic events and now it was happening all over again.

- Distraught and I felt endangered for myself and family.
- I was very angry and anxious as I knew my daughter was well and truly still suicidal and should have been admitted. She in fact walked out of the hospital and straight to a bridge where the police needed to once again get involved to coax her into giving herself up. It was only because I swung into action that the police were quick to get her back into the Emergency Dept again where she was then admitted as an involuntary patient. This caused me a huge amount of stress that no words can describe.
- On each occasion this has taken place it has placed undue stress on myself and the person I cared for. I felt an enormous amount of responsibility to ensure the safety of my person and they felt that they did not matter and weren't important in the grand scheme of things which often led to a worsening of the crisis.
- Scared, and anxious, as I had to cope with a daughter who was suicidal, or at other times very angry. I was the one who had to keep her safe, or keep ourselves safe. This eventually made me also depressed, so that at times I could not function e.g. go to work.
- Frustration, anger and despair

## **SECTION ON: SUPPORT SERVICES MENTAL HEALTH PROFESSIONALS**

**Question 3. Any further comments about support services YOU would like to access or have previously accessed as a CARER or for the PERSON YOU CARE FOR?**

Answered question	23
skipped question	105

- My privately funded psychologist has been a godsend. Compassionate, caring, supportive, and trained in being able to skill me up so that caring for someone is no longer done at the sacrifice of my own mental and physical wellbeing. It's a learning process. But one that is so incredibly vital to the viability of not only my relationship, but the stability of my partner.
- Group therapy and individual psychoanalytic psychotherapy - Conversational Model.
- Group therapy for those with similar diagnoses with a qualified therapist who understands the condition well
- Would be nice to be able to access services for culturally and diverse communities as there is always the associated stigma with mental illness and meeting people from similar situations and backgrounds would be a great support.

- Since we saw more than one psychiatrist/paediatrician/mental health worker over the years, the results were mixed. The only professional who was a constant has been our GP.
- The answers to the question above relate only to the early intervention service
- XXX at the XXX centre ran an informative and effective workshop for carers of bpd sufferers. Carer support network in XXX has been helpful. XXX from XXX clinic (*private*) has made himself available out of hours and consistently communicated and informed both ourselves and our daughter in relation to her illness and subsequent recovery.
- I have had great support from carers respite connections /XXX as a carer. Providing petrol vouchers, movie tickets, weekend away for me as a carer. Counselling, workshops, and support on the telephone
- Psychology is THE most important service for myself as carer and for my daughter also
- They often say they are supportive and show sympathy but then they will say that because he refuses to acknowledge his issues and refuses to engage that they are unable to help usually because of the Mental Health Act - even when his behaviour is life threatening to others.
- Education on BDP and detecting warning signs
- ARAFMI - advocacy was instrumental in resolving conflict with AMHS and clinicians unwilling to take on board the wishes of our young person and our family
- At times of ongoing crisis it would be very useful to have long-term care as an option. It is pointless sending someone back on the streets simply because the demand is too high to provide care.
- I think I've covered it all in previous questions
- I would like to find a support group for relatives of BPD sufferers.
- We and our daughter have been fortunate to have two different Key Workers who were exceptionally supportive; each spent a lot of time consulting with my wife and/or me, and took a considerable amount of our normal caring role.
- Private psychologist, unconnected to consumer's situation were very supportive. Anyone connected with consumer was defensive, unsupportive, and didn't maintain confidentiality!
- I have had access to specific MH carer supports but unfortunately these are not always available when you really need them, such as at time of crisis. This is due to reasons such as crisis taking place outside of work hours (night, weekend), part time nature of employment of these workers or workers not being available in some rural centres. Very difficult to feel supported over phone.
- I have had counselling through Carers SA with a private counsellor who was very supportive of me as a carer coping with my daughter's mental illness though not specifically with BPD

- To my knowledge, they don't exist in XXX or XXX
- When it comes to care or support for Carers, this is not existent. The patient is the only concern - ever!
- I have registered to attend facilitator training at XXX Centre, which provides eight week courses for carers of persons with BPD, but I would like to see a program similar to the Family Connections program run in the US and devised by Perry Hoffman, set up in Melbourne. I have been attempting to have this program started here, but so far have not been able to - because of funding I believe. As many people with BPD refuse to access help, the care is left for their families, and the families do not know what to do!
- I would like to be able to access a program like the Family Connections program run in the States.

**Question 8.** *Do you have any further comments about this section?*

<b>Answered question</b>	<b>16</b>
<b>Skipped question</b>	<b>112</b>

- My partner through her own self-advocacy has created a mental health plan, which details stable times and times of crisis. Through that, she has identified safe spaces at work, home, and linked in friends, me, her colleagues, and her mental health team to allow us all to support each other in supporting her. Having recently had the sad opportunity to test this out, while there were a few kinks in the process, this has been instrumental in early intervention and awareness, escalation of medical assistance, and then ultimately a 2 day visit to the XXX ward at XXX hospital.
- Private Psychoanalyst very helpful and practical.
- My daughter had to stop using drugs before the GP would refer her on. This took a month, and by then the crisis was mostly over - the severity not so intense.
- Public hospitals have been totally ineffective in responding to or helping calmly handle any crisis. the lengthy delays and poor attitude as well as insufficient training/experience/knowledge/understanding has often exacerbated the crisis and caused lasting and present distrust and reluctance to seek further help from "health professionals" for our daughter and even making us hesitant before giving our trust to new people who want to help treat her.
- I don't really have anyone to access anymore. The help I received was when my daughter was younger.
- She wanted access to these support services but she was not able to, not because she was refused access, but because of her own internet conflict in regards to being assertive enough to ask for help. Ideally, she wanted these support services to be "mind readers" and reach out to her so she doesn't have to reach out to them.

- I have had to communicate with my daughter's mental health care workers in the past through letters, faxes and phone calls, as she lived elsewhere. Response has been patchy, even though at times the situation was dire, e.g. when she was causing enormous damage to her (my) family or when she was psychotic. The worst have been the psychiatrists, who never (with the exception of one two line letter) answered letters or would enter into a human dialogue with me. It is ironic that for the most part they become wealthy in their chosen profession, whilst mental health carers receive nothing, often becoming ill (as I have) through the intolerable stresses of their situation.
- I've had to deal with crisis mostly by myself. cat team were non responsive when I called them to say my daughter held a knife to my throat. They wanted to talk to her, well when she goes off talking is the last thing she wants to do to a person on the telephone. My son and I have to calm her down there was no support at my local hospital. We were alone in dealing with some awful violent situations where police were called because we didn't feel safe. I had to carry out the police calls on several occasions to prove to her that I meant it. Sadly it's not the always the best solution to use. I knew of nothing else to do. The police were a bit helpful and did come into the house to speak with my daughter and me. I didn't press any charges on my daughter. She did self-harm afterwards as she usually does to help her to feel better. As she tells me so. If we carers have more knowledge on what to do in these situations then we can be more in control of what to do and decide what's best for her.
- Mental Health Services have responded in the past immediately when police have attended but do not do so anymore - they are waiting for him to come to them because of his "lack of insight" and acceptance of his condition..
- Client doesn't ask for treatment
- The mental health NGO workers are great
- I have been extremely unhappy over the years regarding the social workers and public mental health's commitment to their clients in the public mental health service. My fears with extreme behaviours and putting herself and her family at risk with violence for many years did not seem a priority. When issues were raised after discovering she was subject to sexual abuse, she was never EVER provided treatment to deal with these issues. She had suicidal tenancies from the age of 10.
- Psychiatrist will not receive calls outside appointment time.
- My son hasn't seen a Psychiatrist for many years. He does have an appointment with one next week which will be the first time in many years.
- I am unclear whether section 7 refers to me or the person I care for -- I responded assuming it meant my daughter, but then the "none" response refers to carer. If it meant me as carer, my response would be "None".
- When engaged with a private Psychiatrist responses were generally good and effective. We have been fortunate in having had the same public MH case manager for 14 years. This has meant that responses have generally been very good and appropriate as worker has a great understanding of

the person I have cared for. This was not always the case in the early years. GP's responses have been at times inappropriate and often without consultation with MH professionals.

### **SECTION ON: RESEARCH: CHILDHOOD AND ADOLESCENCE STATISTICS**

*Question 1. Do you have any further comments about this section?*

Answered question	3
Skipped question	125

## APPENDIX 2.

### SURVEY: EXPERIENCE OF CARERS SUPPORTING SOMEONE WITH THE DIAGNOSIS OF BORDERLINE PERSONALITY DISORDER

#### Page: Demographics (Carer)

##### 1. In which State/Territory do you live?

QLD

NSW

ACT

VIC

TAS

SA

WA

NT

##### 2. Location

Capital City

Regional Town

Remote Town

##### 3. What is your Gender?

Male

Female

##### 4. What is your Age?

Under 18

18-24

25-39

40-49

50-64

Over 65

##### 5. What is your Marital status?

Single

Spouse/Partner

Separated/Divorced

Widowed

**6. Are you of Aboriginal or Torres Strait Islander descent?**

Yes

No

**7. What is your country of birth (if not Australia)?**

**8. If you were not born in Australia, how many years have you lived here?**

**9. What language do you speak at home (if other than English)?**

**PAGE: BACKGROUND INFORMATION (CARER)**

**1. What relationship to you have with the person you care for? I am their:**

Parent / Guardian

Spouse/ partner

Sibling

Son / Daughter

Friend

Other

**2. What is the gender of the person you care for?**

Male

Female

**3. What is the age of the person you care for?**

Under 18

18-24

25-39

40-49

50-64

Over 65

**4. What is the marital status of the person you care for?**



Single

Spouse / Partner

Separated / Divorced

Widowed

**5. Is the person you care for of Aboriginal or Torres Strait Islander descent?**

Yes

No

**6. In what country was the person you care for born ( if not Australia)?**

**7. If the person you care for was not born in Australia, how many years have they lived here?**

**8. In what language does the person you care for speak at home (if other than English?**

**1. What is the primary diagnosis of the person you care for?**

Borderline Personality Disorder (BPD)

Anxiety Disorder

Post Traumatic Stress Disorder (PTSD)

Obsessive Compulsive Disorder (OCD)

Bipolar Disorder

Schizo-affective disorder

Eating disorder

Don't know

**PAGE: 5**

**1. Does the person you care for have any other mental health diagnoses?  
Select all options that apply.**

Borderline Personality Disorder

Anxiety Disorder

Post Traumatic Stress Disorder (PTSD)

Obsessive Compulsive Disorder (OCD)

Bipolar Disorder

Schizo-affective Disorder

Eating Disorder

No other diagnoses

Don't know

**2. If known, what medications does the person you care for take for mental health issues?**

None

Anti Depressants

Anti Anxiety

Anti Psychotic

Don't know

**3. If known but you are not sure of what the medications are for, please list the names here.**

**4. When was the PERSON YOU CARE FOR diagnosed with Borderline Personality Disorder (BPD)?**

Within the last year

1 – 3 years ago

3 – 6 years ago

5 – 10 years ago

Longer than 10 years ago

Don't know

**5. Which medical professional made the diagnosis of BPD?**

General Practitioner (GP)

Psychiatrist

Psychologist

Mental Health Nurse

Don't know

**6. Did that medical professional explain to YOU AS A CARER what Borderline Personality Disorder means?**

No

Yes

**7. Do you have any further comments about this section?**

**PAGE: IMPACT OF MENTAL HEALTH SUPPORT SERVICES ON YOU AS A CARER**

**1. As a carer for someone with BPD, please rate how challenging each of the following has been for YOU:**

	Very Challenging	Challenging	Neutral / Not Challenging	Not applicable
--	---------------------	-------------	------------------------------	----------------

Unable to access support as a carer

Lack of support options for me as a carer

Services not available in my local area

Financial cost of accessing services as a carer

**2. From the following support services that YOU have accessed as a CARER, how HELPFUL / SUPPORTIVE have the services been? Select 'N/A' on the right hand side of the scale for any services you have not previously used.**

	Very Unhelpful	Unhelpful	Neutral	Helpful	Very Helpful	N/A
--	-------------------	-----------	---------	---------	-----------------	-----

Education and information  
About BPD

Support from my GP

Support from other mental  
health professionals

Counselling for me as a carer

Carer support groups

**3. Have YOU wanted to access support for yourself as a CARER but not been able to?**

No

Yes

**4. Rate how each of the following has prevented you from being supported as a CARER of someone with BPD?**

	Prevented	Neutral	Has not Prevented	N/A
--	-----------	---------	----------------------	-----

Unable to access support when needed

Not being taken seriously

Cost of support services

Lack of carer support available

**5. Do you have any further comments about this section?**

**PAGE: IMPACT OF MENTAL HEALTH SUPPORT SERVICES FOR THYE PERSON YOU ARE CARING FOR**

**1. From your perspective, rate what has caused the most anxiety or been the hardest / most challenging aspect for the**

PERSON YOU CARE FOR?	Very Challenging	Challenging	Neutral	Not Challenging	N/A not an issue
Fear of losing mental health support					
Fear of losing a long term therapist					
Lack of long term / consistent support					
Discrimination because of Borderline Personality Disorder diagnosis					
Not being taken seriously					
Being treated badly					
Not feeling respected					
Unable to access support when needed					
Lack of choice of support services					
Long waiting lists / times to see mental health professionals					
Services not available in our local area					
Financial cost of accessing services					
Unable to comment					

2. If known, from your perspective as a carer, how HELPFUL / SUPPORTIVE have the following mental health services been for the PERSON YOU CARE FOR? Select 'N / A' on the right hand side of the scale for any services the person you care for has not accessed, or if you don't know.					
	Very Helpful	Unhelpful	Neutral	Helpful	Very Unhelpful N / A
Identifying early warning signs					
Developing a crisis plan					
Education and information about BPD					
Meditation					
Hypnotherapy					
Psychotherapy (long term and/or regular therapist)					
Cognitive Behavioural Therapy (CBT)					
DBT					
Trauma Counselling					
Hospital admission					

Mental health support groups  
(e.g. depression, anger  
management, PTSD, etc.)

Community support groups  
(e.g. art therapy, friendship  
groups, etc.)

**3. If known, has the PERSON YOU CARE FOR wanted to access any of these support services but has not been able to?**

No

Yes

Don't know

**4. If known, from the above services in the past, what has contributed most to support the recovery to the PERSON YOU CARE FOR? For example, support from GP or Psychologist, Group Therapy, Mental Health Team, medication, etc.**

**5. If known, from the above services, what has been the least helpful / prevented / interfered the most with the recovery of the PERSON YOU CARE FOR? For example, unable to access support when they needed to, not taken seriously, affordability of availability of support services, etc.**

**6. Has the person you care for been admitted into hospital for issues related to BPD in the last:**

3 months

6 months

9 months

18 months

More than 18 months or no admissions

## **PAGE: GENERAL ADMISSIONS**

**1. Does / has a GP supported YOU as a CARER?**

No

Yes

**2. Does / has a GP supported the PERSON YOU CARE FOR with issues relating to BPD?**

No

Yes

**3. Does a GP provide You with personal counselling for issues related to being a CARER?**

No

Yes

**4. How long have YOU as a CARER been receiving personal counselling from a GP?**

Less than 6 months

6 - 12 months

1 – 2 years

2 – 5 years

5 – 10 years

Longer than 10 years

**5. Has a GP referred YOU to any of the following CARER support services / mental health professionals?  
Select all that apply?**

Mental health team

Psychiatrist

Psychologist

Social Worker

Occupational Therapist

Counsellor (other)

Carer support groups

No referrals given

**6. Has your GP referred the PERSON YOU CARE FOR to any of the following mental health professionals?**

Mental health team

Psychiatrist

Psychologist

Social Worker

Occupational Therapist

Counsellor (other)

Carer support groups

No referrals given

**PAGE: PUBLIC & PRIVATE MENTAL HEALTH SERVICES**

**1. Select from the following options which one best describes the PERSON YOU CARE FOR access to public and / or private mental health / hospital services?**

Only use public mental health services / hospitals

Only use private mental health services / hospitals

Use mostly public mental health services / hospitals and some private

Use mostly private mental health services / hospitals and some public

Don't know

## **PAGE: HOSPITAL ADMISSIONS - PUBLIC**

**1. Has the PERSON YOU CARE FOR ever been admitted to a public hospital because of issues relating to Borderline Personality Disorder (BPD)?**

Don't know

No

Yes

## **PAGE: HOSPITAL ADMISSIONS - PUBLIC**

**1. Approximately how many hospital admissions has the PERSON YOU CARE FOR had in the past 3 years because of issues relating to BPD**

None

1

2

3

4

5 or more

**2. If known, has the PERSONAL YOU CARE FOR ever been admitted into hospital involuntarily (i.e. without their request or consent to be admitted)?**

No

Yes

Don't know

**3. If known, what has been the longest stay in hospital for the PERSON YOU CARE FOR for mental health issues?**

Not applicable

1 day

3 days

1 week

2 weeks

3 or more weeks

Don't know

**4. When the PERSON YOU CARE FOR was admitted into hospital, have you ever been involved in:**

Their assessment process

Their treatment

Ongoing management

Decisions about the person you care for

Discharge planning

No involvement

**5. Have you ever asked for the PERSON YOU CARE FOR to be admitted into hospital because of mental health issues but been refused?**

Don't know

No

Yes

**PAGE: HOSPITAL ADMISSIONS - PUBLIC**

**1. What were the main reasons for the request for the PERSON YOU CARE FOR to be admitted due to mental health issues? Select all that apply.**

Suicidal behaviours

Self-harm behaviours

Out of control

Life in chaos

Depression

Anxiety

Drug / Alcohol problems

Don't know

**2. If known, who refused to admit the PERSON YOU CARE FOR into hospital?**

General Practitioner (GP)

Psychiatrist

Psychologist

Case Manager

Mental Health Unit Manager

Director of Nursing

Clinical Director

Don't know



**3. If known, please provide further comments / information relating to this refusal of hospital admission**

**4. Briefly describe how You as a CARER FELT and what the IMPACT was on not being able to admit the person you care for into hospital.**

**5. Have YOU as a CARER ever been admitted into hospital for issues relating to YOUR MENTAL HEALTH or the burden of caring for someone diagnosed with BPD?**

No

Yes

**6. If You have been admitted, how many admissions have YOU as a CARER had in the past 3 years?**

None

1

2

3

4

5 or more

## **PAGE: HOSPITAL ADMISSIONS - PRIVATE**

**1. Has the PERSON YOU CARE FOR ever been admitted to a private hospital / clinic because of issues relating to Borderline Personality Disorder (BPD)?**

No

Yes

Don't know

## **PAGE: HOSPITAL ADMISSIONS - PRIVATE**

**1. Approximately how many hospital admissions has the PERSON YOU CARE FOR had in the past 3 years because of issues relating to BPD?**

None

1

2

3

4

5 or more

Don't know

**2. If known, what has been the longest stay in hospital for the PERSON YOU CARE FOR for mental health issues?**

Not applicable

1 day

3 days

1 week

2 weeks

3 or more weeks

Don't know

**PAGE: SUPPORT SERVICES - MENTAL HEALTH PROFESSIONALS**

**1. If known, which mental health professionals has the PERSON YOU CARE FOR seen specifically for issues relating to Borderline Personality Disorder (BPD)? Select all that apply.**

General practitioner (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

None – have not accessed support from mental health professionals

Don't know

**PAGE: SUPPORT SERVICES - MENTAL HEALTH PROFESSIONALS**

**1. If known, how long has the PERSON YOU CARE FOR been accessing support from mental health professionals?**

Less than 6 months

6 – 12 months

1 – 3 years

3 – 6 years

5 – 10 years

More than 10 years

Don't know

**2. To what extent has each of the following mental health professionals supported YOU as a CARER for issues relating to caring for a person diagnosed with BPD?**

Very Supportive	Supportive	Neutral	Not Supportive	N/A not used
-----------------	------------	---------	----------------	--------------

Select all options that apply

General Practitioner (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

None – have not accessed support as a carer

Other – (please specify)

**3. Any further comments about support services YOU would like to access or have previously accessed as a Carer or for the PERSON YOU CARE FOR?**

**4. Has a mental health professional helped YOU understand early warning signs or when the person you care for might be more at risk of suicide or self harm?**

No

Yes

**5. Have YOU received a CRISIS PLAN for the person you are caring for?**

No

Yes

**5. When the PERSON YOU CARE FOR is in a crisis and have requested help, on average how long does it take for a mental health professional to respond to them?**

The same day

Within 2 days

Between 2 days – 1 week

Longer than a week

Do not respond

Don't know

**7. From the services listed below, please rate how responsive each has been when the PERSON YOU CARE FOR is in a crisis?**

Very Responsive	Responsive	Not Responsive	N/A not used
-----------------	------------	----------------	--------------

Select all options that apply

General Practitioner (GP)

Psychiatrist

Psychologist

Mental Health Worker

Occupational Therapist (OT)

Social Worker

None – have not accessed support as a carer

Other – (please specify)

#### 8. Do you have any further comments about this section?

### PAGE: GENERAL SUPPORT SERVICES

1. From your perspective as a carer, please rate any of the following support services that the PERSON YOU CARE FOR has accessed. Select 'N/A' on the right hand side of the scale for any services the PERSON YOU CARE FOR has not previously accessed, or if you don't know.

	Very Unhelpful	Unhelpful	Neutral	Helpful	Very Helpful	N/A
Crisis lines						
General support groups						
Financial support						
Housing support						
Gambling support						
Drug / Alcohol support						
Relationship counselling						
Women's shelter						
Youth shelter						

### PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR

1. Would you like to continue with this section?

No – prefer to skip section

Yes – continue with this section

### PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR

1. If the PERSON YOU CARE FOR sought support after having suicidal behaviours, who did the PERSON YOU CARE FOR seek support from?

Don't know

General Practitioner (GP)

Psychiatrist

Psychologist

Mental Health Worker

Hospital

Did not seek support

Skip this section

## PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR

### 1. If known, what was the longest time it took to get support for the PERSON YOU CARE FOR after requesting it?

Don't know

Same day

1 - 2 days

2 - 3 days

3 – 5 days

5 days – 2 weeks

Longer than 2 weeks

Did not get a response

Skip this section

## PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR

### 1. If YOU as a CARER sought support after the person you care for displayed these behaviours, who did YOU seek support from? Select all that apply.

General Practitioner (GP)

Psychiatrist

Psychologist

Mental Health Worker

Hospital

I did not seek support as a carer

Skip this section

## PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR

### 1. What was the longest time it took for YOU to get support as a CARER at these times after requesting it?

Same day

1 - 2 days

2 - 3 days

3 – 5 days

5 days – 2 weeks

Longer than 2 weeks

Did not get a response

Skip this section

## **PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR**

**1. If known, as a result of the PERSON YOU CARE FOR self harming or attempting to end their life, did the PERSON YOU CARE FOR seek medical attention?**

Don't know

No

Yes

Prefer not to answer

Skip this section

## **PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR**

**1. Who did the PERSON YOU CARE FOR see for medical attention relating to harming themselves or attempting to end their life?**

Don't know

General Practitioner (GP)

Hospital – Emergency Department

Prefer not to answer

Skip this section

## **PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR – EMERGENCY DEPARTMENTS**

**1. What is the longest time the PERSON YOU CARE FOR had to wait in a emergency department for treatment of self inflicted injuries?**

Don't know

Immediately

1 – 4 hours

5 – 8 hours

More than 8 hours

Prefer not to answer

Skip this section

## PAGE: SUICIDAL, SELF HARMING AND RISKY BEHAVIOUR

**1. If known, as a result of the PERSON YOU CARE FOR harming themselves, was the PERSON YOU CARE FOR referred to a mental health professional (for example psychiatrist, psychologist, social worker, mental health team, etc)?**

No

Yes

Don't know

Skip this section

## PAGE: RESEARCH: CHILDHOOD AND ADOLESCENCE STATISTICS

**1. Did you notice anything unusual in infancy or toddlerhood?**

Colic

Excessive separation anxiety

Inability to be consoled

Inability to self-soothe

Sensory problems

Picky eating

Poor temperament

Sensitivity

Moodiness

Motor delay

Cognitive delay

Social delay

Verbal delay

Physical abuse (of this child)

Sexual abuse (of this child)

**2. Did you notice anything unusual in childhood?**

Poor temperament

Anger

Sensitivity

Moodiness

Impulsivity

Difficulty making friends or few friends

Conflict with authority figures

School refusal or truancy

Frequent lying or deception

Suspension or expulsion

Multiple schools

Bully victim

Bully perpetrator

Victim of rape

Poor grades

Learning disability or special education

Body images issues

Emptiness

Boredom

Verbal abusive outbursts

Alcohol abuse

Substance abuse

Physical abuse (of this child)

Sexual abuse (of this child)

### **3. Did you notice anything unusual in adolescence?**

Moodiness

Sensitivity

Poor temperament

Anger

Impulsivity

Recklessness

Property destruction

Arrests

Theft



Alcohol abuse

Anorexia

Bulimia

Body image issues

Emptiness

Boredom

Hallucinations

Delusions

Homicidal ideation

Paranoia

Odd thinking or perceptions

Physical abuse (of this child)

Sexual abuse (of this child)

#### **4. Did you notice anything else unusual in adolescence?**

Violence victim

Aggression

Frequent lying or deception

Verbally abusive outbursts

Difficulty making or few friends

Promiscuity

Pregnancy

STDs

Rape victim

Fights

#### **5. What first prompted you to seek evaluation?**

Anger problems

Temper tantrums

Behaviour problems

Teacher recommendation

School refusal

Doctor recommendation

Mood disturbances

Eating disorder

Substance abuse

Police intervention or legal issues

Promiscuity

**6. What treatment was initially recommended?**

Therapy

Medication

Hospitalisation

Day treatment

Alcohol/drug rehabilitation

Halfway house

**7. Do you have any further comments about this section?**

## APPENDIX 3.

### ELECTRONIC COPY OF EMAIL USED FOR DISTRIBUTION OF SURVEYS

Hello .....,

Would you support us in forwarding this email throughout your networks requesting recipients to do the same. This is a first of its kind in Australia and we are inviting people to complete a survey. Extensive *national distribution and completion* is vital.

#### **Are you a consumer or carer affected by the diagnosis of Borderline Personality Disorder?**

We are undertaking a national survey to better understand the needs of consumers and carers affected by BPD, to know what supports assisted most and what barriers and gaps there are in accessing help in the current mental health system. The information gathered will be used to inform **current** and **any future initiatives** and advocate for improvement and change in the treatment and care for persons affected by BPD and their carers. A brief report of the findings will be written and will be made available on the Network's website of [www.pmhccn.org](http://www.pmhccn.org) later this year.

#### **The surveys will not identify you!**

Survey links:

**Consumer** Experiences of Care for people affected by Borderline Personality Disorder

<https://www.surveymonkey.com/s/CVCCZJT>

**Carer** Experiences of Care for people affected by Borderline Personality Disorder

<https://www.surveymonkey.com/s/CVWJ63K>

#### **Go into the draw for one of ten \$50 prepaid Visa card**

The surveys are very comprehensive and will take a while to complete, but please be patient as this is the first opportunity of gaining as much information from consumers and carers as possible. To acknowledge your assistance, we are offering five \$50 pre-paid Visa cards to consumers and five \$50 pre-paid Visa cards to carers who complete the survey and the voucher link. We will randomly select these people to receive these cards.

-----

We are also establishing an '*Informal Consumer and Carer Group*' for people affected by the diagnosis of *Borderline Personality Disorder*. The purpose is to have a consumer and carer group which we can refer to and obtain information from, to assist the continuing advocacy for the provision of better services throughout the Australian public and private mental health sectors.

**People joining, can choose only to be identified by their email address.**

To join, click onto this link:

**Informal Consumer Carer Group for people affected by Borderline Personality Disorder**

<https://www.surveymonkey.com/s/QDZRZYN>

Thank you for your interest and support in distribution this email throughout your networks.

Regards, Janne

---

Ms. Janne McMahon OAM  
Independent Chair  
Private Mental Health Consumer Carer Network (Australia)  
PO Box 542, MARDEN SA 5070

[www.pmhccn.org](http://www.pmhccn.org)

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## ACRONYMS

AMA	Australian Medical Association
APA	American Psychiatric Association
ASPD	Anti-Social Personality Disorder
BPD	Borderline Personality Disorder
CBT	Cognitive Behaviour Therapy
CDMS	Centralised Data Management Service
CSA	Childhood Sexual Abuse
CVT	Comprehensive Validation Theory
DBT	Dialectical Behaviour Therapy
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Emergency Department
ERG	Expert Reference Group
ICD-10	International Classification of Diseases – 10 <sup>th</sup> Edition
ITP	Interpersonal Therapy
MACT	Manual Assisted Cognitive Behaviour Therapy
MBT	Mentalization-based Therapy
MBCT	Mindfulness-Based Cognitive Therapy
NESARC	National Epidemiologic Survey on Alcohol and Related Conditions
NICE	National Institute for Health and Clinical Excellence
NCS-R	National Comorbidity Survey Replication
NSW	New South Wales
NZ	New Zealand
ONS	Office of National Statistics (UK)
PMHA	Private Mental Health Alliance
PMHA CCN	Private Mental Health Alliance Consumer and Carer Network
PTSD	Post Traumatic Stress Disorder
QIP	Quality Improvement Project

QOL	Quality of Life
SFT	Schema-focussed Therapy
SRO	Senior Research Officer
TFP	Transference-focussed Psychotherapy
TOR	Terms of Reference
UK	United Kingdom
USA	United States of America

